Participation of the visually impaired elderly

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Participation of the visually impaired elderly: determinants and intervention

Colofon

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1

Introduction

1.1 Introduction

In 2002, the World Health Organization (WHO) estimated the total number of visually impaired persons worldwide at 161 million [1]. Visual impairment is primarily a problem of the elderly; 79% of the visually impaired persons in the Netherlands are aged 65 years and over [2]. Due to the proportional rise in the aging population the total number of visually impaired elderly people is expected to increase in the future.

Previous research on vision loss was mostly focused on clinical (e.g., visual acuity, visual field) and functional outcome measures (e.g., reading speed, mobility, performance of daily activities) [3-9]. As a consequence, limited knowledge exists on social outcomes of vision loss. The Inventory of applied scientific research on visual impairment [4] reveals that both nationally, as well as internationally, the topic of participation in society is neglected. That is in contrast with the policy of the WHO that underlines the importance of participation as an outcome measure of disease in the International Classification of Functioning, Disability and Health (ICF) [10].

To promote research on participation of visually impaired people, the Netherlands Organization for Health Research and Development (ZonMW) initiated the research program 'InSight' (2005-2008). This program continued the efforts of the InSight society that was launched in 1998. The InSight society aimed to narrow the gap between research practice by a focus on the application of study results into low-vision rehabilitation practice. Accordingly, one of the conditions of the ZonMW research program InSight was that research projects should involve a collaboration between a university department and at least one center for low-vision rehabilitation. The research project presented in this thesis was supported by ZonMW InSight and was performed in close collaboration with Royal Dutch Visio, formerly known as Visio (region North Netherlands).

The central theme of this thesis is participation of the visually impaired elderly. This introductory chapter starts with the epidemiology of visual impairment and the consequences of vision loss for daily life. Furthermore, an overview of low-vision rehabilitation in the Netherlands will be presented. Next, the theoretical framework and the concept of participation will be introduced. The chapter ends with the objectives and the research questions, followed by the outline of the thesis.

1.2 Visual impairment

1.2.1 Definition

There are many definitions for visual impairment and blindness. Visual impairment is commonly defined in terms of visual acuity and visual field, and measured in the better eye with the best possible correction. The most commonly used definition is that proposed

by the World Health Organization. In the International Statistical Classification of Diseases and Related Health Problems (ICD-10)[11] low vision is defined as “visual acuity <1/3 (but ≥ 3/60) or a corresponding field <30 degrees”. Blindness is defined as “a visual acuity <3/60 or corresponding visual field <10 degrees”. In this thesis the term visual impairment will be used to refer to low vision and blindness.

1.2.2 Prevalence

Globally, in 2002 more than 161 million people were visually impaired [1]. Visual impairment is unequally distributed across age groups. Worldwide more than 82% of blind people are aged 50 years and older [1]. There have been many population-based studies on the prevalence and causes of visual impairment. One of these studies, The Rotterdam Study [12], was performed in the Netherlands. This study showed that in women, the prevalence of low vision ranged from 0.1% in those aged 55-64 years to 12.5% in those aged 85 years. The prevalence of blindness among women ranged from 0.1% (55-64 years) to 4.7% (≥85 years). In men, the prevalence of low vision ranged from 0.1% (55-64 years) to 9.0% (≥85 years) and the prevalence of blindness ranged from 0.1% (55-64 years) to 1.1% (≥85 years). A more recent Dutch study [2] estimated the number of elderly people with a visual impairment based on prevalence rates from population-based studies on blindness and low vision in the Netherlands, Western Europe, the United States and Australia. This study estimated that in the Netherlands in 2008, a number of 234,000 persons had low vision and 77,000 persons were blind. Of these visually impaired persons, 79% were 65 years and older. It is estimated that between 2005 and 2020 the number of visually impaired elderly persons will increase by 19% [13].

1.2.3 Causes

The most frequent causes of visual impairment are age-related macular degeneration, cataract, glaucoma, diabetic retinopathy, and refractive error [2,6,12,14-16]. Age-related macular degeneration (AMD) is the most frequent cause of adult blindness, especially in persons aged 70 years and over [12,16,17]. AMD is a progressive disorder of the macula, which is located in the center of the retina, and causes a loss of the central vision. Peripheral vision is hardly ever affected by AMD. Risk factors for AMD are advanced age, a family history of AMD, and cardiovascular risk factors such as hypertension and smoking [18].

Cataract is the most frequent cause of bilateral visual impairment and the second frequent cause of blindness [12]. Cataract refers to lens opacities that interfere with vision function [18]. The progression of cataract is typically slow, with gradual vision loss over months to years [18]. Risk factors for cataract are advanced age, a family history of cataract, eye injury, medications such as cortisone, and environmental factors (e.g., ultraviolet B light, UVB).

In contrast with AMD and cataract, glaucoma affects relatively younger age groups [16]. Glaucoma comprises a group of disorders characterized by glaucomatous damage of the optic nerve and is associated with early peripheral visual field loss [18]. Late in the disease process, glaucoma also affects central vision. Risk factors include high intraocular pressure, a family history of glaucoma, advanced age, high degree of myopia, hypertension, and diabetes mellitus [18].

Diabetic retinopathy (DRP) is a complication of diabetes mellitus characterized by changes in the small blood vessels (capillaries) in the retina. The prevalence of visual impairment due to DRP is relatively low (≤0.8%) [16]. Among diabetics, however, the prevalence of DRP ranges from 22% to 49% [19]. The duration of diabetes mellitus is a risk factor for DRP [18].

Although refractive errors are not considered as an eye disease, they are a frequent cause of reduced visual acuity. A refractive error is a failure of the ability of the eye to sharply focus images on the retina which causes a blurred vision [20]. The vision can be blurred for distant objects, for near objects, or for both. Common refractive errors are myopia (distant objects are blurred), hyperopia (close objects are blurred), astigmatism (blurred vision at all distances), presbyopia (close objects are blurred due to aging of the lens in the eye), and anisometropia (the two eyes have unequal refractive power) [20].

1.2.4 Consequences

Vision loss has a profound impact on daily functioning [9,21,22] and is regarded as an important contributor to disability [23]. Visually impaired persons experience many restrictions in daily life due to vision loss. Vision loss may not only lead to difficulties in performing activities [3,7,9,24-28] but also to a loss of activities [8,28], and consequently poses a severe threat to the independence of visually impaired persons [29-31]. Vision loss and its consequences require substantial psychosocial adjustment, a process many visually impaired persons are struggling with [32,33]. The psychosocial impact is profound, evidenced by the elevated risk for depression [34-37] and the high level of emotional distress [38]. Furthermore, vision loss has a negative impact on health-related quality-of-life [3,38-43].

1.3 Low-vision rehabilitation

1.3.1 Low-vision rehabilitation in the Netherlands

In 2004, the Dutch Ophthalmic Society developed evidence-based guidelines for the referral of persons with irreversible vision loss to low-vision rehabilitation [44,45]. In most cases, it is the ophthalmologist who performs a complete ophthalmic examination. According to the guidelines, it is recommended that persons with a visual acuity <0.5, a reading acuity of <0.25, a visual field defect within 30 degrees of fixation or other severe impairments in visual field (e.g., hemianopsia) should be referred to low-vision rehabilitation. In addition,

persons with relevant vision-related problems in daily life which cannot be addressed by interventions in the standard ophthalmic practice, and which can potentially be solved by visual rehabilitation, should also be considered for referral to low-vision rehabilitation. Low vision rehabilitation aims to assist people in adequately coping with their visual impairment in daily life in order to optimize their participation in society. In the Netherlands, there are two major types of low-vision rehabilitation: monodisciplinary low-vision rehabilitation, which is provided by specialized optometrists, and multidisciplinary low-vision rehabilitation provided at regional rehabilitation centers.

The optometrists assesses a persons' visual functioning and assesses the problems related to vision loss as experienced in daily life. In addition, the optometrist gives advice about the use of low-vision aids, such as magnifiers, and adjusts these aids to the individual person. If visually impaired persons have complex rehabilitation needs, the optometrists will refer them to a multidisciplinary low-vision rehabilitation center. Optometrists usually works for firms which are based in hospitals or in the community at an optician.

Multidisciplinary low-vision rehabilitation services are provided at regional outpatient centers. After a general intake in which the rehabilitation needs are assessed, a low-vision specialist or optometrist examines the visual functioning (e.g., visual acuity, visual field, contrast sensitivity). Regional low-vision rehabilitation centers offer training in the use of devices (e.g., magnifiers), training in the use of residual vision, and training in activities of daily living (ADL). The training is performed by low-vision therapists and occupational therapists. Furthermore, these centers provide individual and group counseling offered by social workers or psychologists. In addition to these outpatient centers, some organizations offer inpatient facilities, for example for adults who have multiple handicaps or schooling for children. These inpatient facilities provide for example job training, training of ADL and mobility, or training in recreational activities.

Until 2008, there were three organizations in the Netherlands that provided multidisciplinary low-vision rehabilitation services, i.e., Visio, Sensis and Bartimeus. In 2008, the boards of Visio, Sensis and De Brink merged together to become the Visio-Sensis-De Brink Group. Since 2010, they operate as one organization, entitled as Royal Dutch Visio. The study that is presented in this thesis was performed among elderly clients of Royal Dutch Visio, formerly known as Visio (region North Netherlands).

1.3.2 Outcomes of low-vision rehabilitation

Internationally, several studies reported on the effectiveness of low-vision rehabilitation services. These studies evidenced the positive impact of interdisciplinary low-vision rehabilitation on functional status [41], visual functioning [46,47], (vision-related) quality of life [41,47-49], emotional well-being [47,49], and coping [50]. In addition, there were studies that reported the effects of interventions that were newly developed interventions

for visually impaired persons. Eklund et al. [51] studied the effect of a health education program and found an improvement in perceived security in daily activities. Other studies developed psychosocial intervention programs (e.g., self-management programs, support groups) and demonstrated a positive impact on adaptation to vision loss [52,53], mental health [33,52-57], perceived autonomy [54], empowerment [58], self-efficacy [52,53,55,59] and self-confidence [33,58]. Moreover, these studies reported an increase in ADL-functioning [54], an increase in active problem orientation [54], and an increase in activity level [52,53].

In the Netherlands, research on the outcomes of low-vision rehabilitation is limited [4]. An observational study by De Boer et al. [60] compared two types of low-vision rehabilitation services, i.e., optometric services versus multidisciplinary rehabilitation services. The results indicated that people who were referred to optometric services showed less deterioration in mobility at 1-year follow-up compared to people who were referred to multidisciplinary rehabilitation services. There was a small decline in vision-related functioning and a small improvement in adjustment to vision loss in the multidisciplinary rehabilitation services study group [60]. A secondary analysis using Item Respons Theory showed that in the short-term neither of the two low-vision rehabilitation services made any substantial contribution to vision-related quality of life, except for an improvement in the ability to read small print [61]. A follow-up measure at four years after rehabilitation showed that many patients experienced a deterioration in quality of life dimensions over time [62]. Since these results are based on one study, research on the effectiveness of low-vision rehabilitation in the Netherlands is needed.

1.4 Theoretical background

As stated in paragraph 1.2.4, the consequences of a visual impairment are more far-reaching than only the loss of vision. Previous studies among the visually impaired elderly mostly focused on limitations in executing specific activities such as reading, mobility, using public transport etc. Only a few studies investigated the impact of vision loss on participation in daily life and found that visually impaired elderly persons perceive restrictions in participation [22,24,63]. The concept of participation was introduced by the World Health Organization (WHO) in the International Classification of Functioning, Disability and Health (ICF)[10]. The ICF is a multipurpose classification that aims to provide a unified and standard framework for the description of health and health-related states. With the ICF, the WHO underlines the importance of participation as an outcome measure of a health condition. Participation is defined as “involvement in life situations” and represents the societal perspective of functioning. Disability is expressed as activity limitations and as participation restrictions, and is assessed as a variety of role behaviors relevant to everyday life. Besides basic self-care activities this includes more advanced and complex social activities such as work, interpersonal interaction, and leisure activities.

Knowledge about participation of visually impaired elderly people is important, not only from the individual perspective but from the societal perspective as well: it gives an impression to what extent people are integrated in society [64]. In the general elderly population, participation is associated with a reduced risk of cognitive [65] and functional decline [66,67]. Participation has a positive influence on health-related quality of life and well-being [68-70] and those who participate less may be at risk for feelings of loneliness [70-72]. Besides the importance of participation performance, which can be viewed as objective participation [73], it is also important to know how this participation is valued from the individual perspective [68,74-77]. A subjective aspect of participation is for example the satisfaction with participation [73]. It is important to make a distinction between objective and subjective participation because these two concepts represent different aspects of participation as evidenced by the weak correlation [78,79]. Therefore, this thesis will investigate both objective and subjective aspects of participation among the visually impaired elderly.

With respect to the development of low-vision rehabilitation interventions that aim to enhance participation in society, insight is needed in which factors act as barriers or facilitators of participation. According to the biomedical model, which for decades was the predominant approach to study vision loss, it is the disease process itself that primarily determines the consequences of vision loss. This model originally focused on the biological, physiological and clinical outcomes of disease [80]. Differences in physical, psychological and social functioning between persons with the same disease, however, cannot be explained by biological factors only. Persons with the same visual impairment and the same degree of vision loss may experience different participation restrictions. Some visually impaired persons will be able to maintain independence, whereas others will become dependent upon others. Social scientists suggest that interindividual differences can be explained by other factors such as psychological and social factors. The biomedical model, however, does not take these psychological and social factors into account. The biopsychosocial model adopts a broader perspective. It is a multidimensional model which states that in the context of a disease, the biological, psychological and social factors all play a significant role with regard to functioning [81]. The ICF is based on this biopsychosocial model.

In this thesis, the determinants of participation of the visually impaired elderly are investigated according to the biopsychosocial model as presented in the research model in Figure 1.1, with vision loss as the central health condition. The biological component is represented by ‘physical health status’, which includes aspects of physical health and physical functioning. The ‘social status’ component reflects objective aspects of social status (e.g., social network size), as well as subjective aspects (e.g., social support). The ‘psychological status’ component reflects mental health and psychological functioning. To examine the associations of these components with the outcome measures of this

thesis (i.e., participation and loneliness), a hierarchical model approach is applied [82]. It is assumed that vision loss not only directly affects participation and loneliness, but also indirect by the effect of vision loss on health status, social status and psychological status. This research model will be further elaborated in the chapters of this thesis.

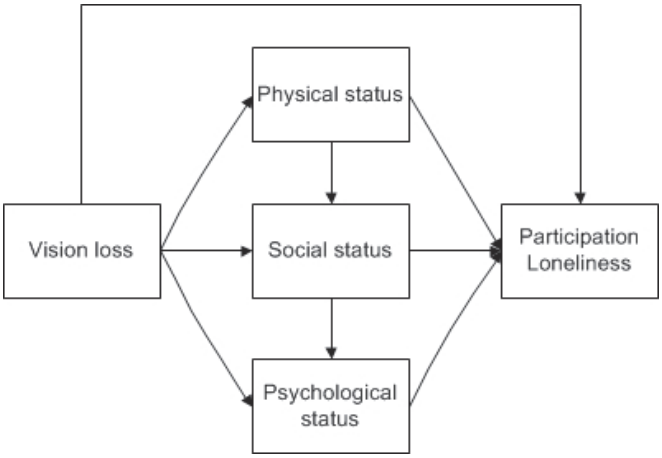

Figure 1.1: Research model

1.5 Objectives

The first objective of this thesis is to get insight in the degree of participation of visually impaired elderly persons and to identify determinants of this participation. A second purpose of the study is to develop a multidisciplinary group rehabilitation program which aims to enhance the level of participation of the visually impaired elderly. The effects of this multidisciplinary group rehabilitation program on participation and on psychosocial and physical functioning will be studied. These goals resulted in the following research questions:

1. To what extent do visually impaired elderly persons participate in society?
2. Which biological, social and psychological factors determine participation of visually impaired elderly persons?
3. What is the prevalence of loneliness among visually impaired elderly persons and what are the determinants of loneliness among visually impaired elderly persons?
4. What is the effect of the multidisciplinary group rehabilitation program on participation (i.e., the primary outcome) and on physical and psychosocial functioning (i.e., the secondary outcomes)?

1.6 Outline of the thesis

To answer the research questions, we performed two studies. First, a cross-sectional survey study was conducted in order to assess the degree of participation and loneliness among the visually impaired elderly and its determinants. Secondly, we developed the multidisciplinary group rehabilitation program *Visually Impaired elderly Persons Participating (VIPP)*. The effectiveness of this program on participation and on physical and psychosocial functioning was tested in a pilot study. Chapter 2 gives a detailed description of the methodology of the survey study and the intervention study.

Chapters 3 to 5 are based on the cross-sectional data of the survey study. Chapter 3 describes the degree of participation of the visually impaired elderly and makes a comparison with data of reference populations (research question 1). Chapter 4 investigates the determinants of participation (research question 2). Chapter 5 describes the prevalence of loneliness among the visually impaired elderly and examined determinants of loneliness (research question 3).

The findings presented in chapters 6, 7 and 8 are based on the intervention study (research question 4). Chapter 6 shows the effects of the multidisciplinary group rehabilitation program *VIPP* on the primary outcome participation. In Chapter 7, the effect of the *VIPP*-program on physical functioning is described, whereas Chapter 8 reports the effects on psychosocial functioning.

In the last chapter, Chapter 9, the main results are summarized and discussed. In addition, implications for future research and rehabilitation practice will be given.

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2

Study design

2.1 Introduction

In order to answer the research questions that are listed in Chapter 1, two studies were performed, i.e., a cross-sectional survey study and an intervention study. Both studies were performed in close collaboration with Royal Dutch Visio, region North Netherlands.

2.2 Survey study

2.2.1 Study participants and study design

The cross-sectional survey study was performed in September 2007 and included visually impaired elderly persons who were referred to Royal Dutch Visio in the year preceding the data collection. Visually impaired elderly persons were eligible for inclusion in the study if they were: (1) aged ≥55 years; (2) able to speak Dutch; (3) able to understand instructions concerning response sets; and (4) referred according to the 'Guidelines on the referral of visually impaired persons to low-vision services' [1,2]. Exclusion criteria were: (1) having a mental disorder (e.g., dementia); (2) having a hearing impairment; and (3) being hospitalized. In the year preceding the data collection, a total of 786 visually impaired elderly clients were registered at Visio – region North Netherlands. Out of these new elderly clients, an age-stratified sample (i.e., <75 years vs. ≥75 years) of 350 visually impaired elderly persons was drawn. Stratification was applied because of expected differences between these age groups.

The 350 visually impaired elderly persons were informed about the survey study by postal mail which was printed in a large font size. Of this sample, 264 persons met the inclusion criteria and were considered eligible for participation in the survey study. Finally, 173 visually impaired elderly persons agreed to participate (response rate 66%). The major reasons for refusal were: the interview takes too long or is perceived too tiresome, a lack of interest, health problems, and a lack of time. Figure 2.1 shows a flow diagram of the inclusion of the study participants.

Data for the survey study were collected by means of telephone interviews. These interviews were performed by experienced interviewers, who received an additional training in interviewing visually impaired elderly persons. We performed seven pilot interviews with visually impaired elderly persons who were doing voluntary work as a host(ess) at Visio. These pilot interviews resulted in a minor revision of the interview schedule.

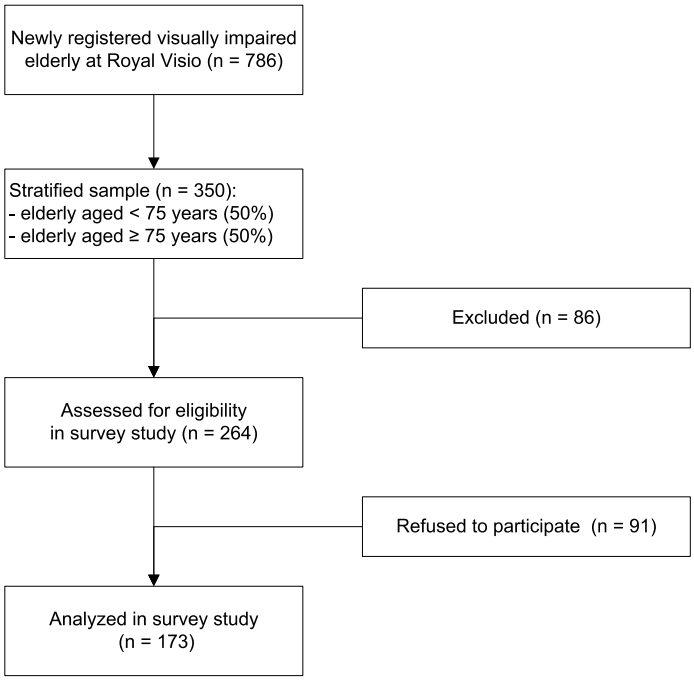

Figure 2.1: Flow diagram of inclusion of the study participants in the survey study

2.2.2 Reference data

In order to compare the degree of participation and loneliness of the visually impaired elderly with normally sighted elderly, we used data of reference populations. For this purpose we had the disposal of three reference data sources: (1) National Survey on Living Conditions (POLS) of Statistics Netherlands (CBS) [3,4]; (2) the Amenities and Services Utilization Survey (AVO) of the Social and Cultural Planning Office (SCP) [5]; and (3) the Longitudinal Aging Study Amsterdam (LASA) [6]. Furthermore, a frequency matched sample of the LASA was used (n=258) in order to make a comparison on the prevalence and the degree of loneliness. The sample was matched on age, gender and partner status.

2.2.3 Outcome measures: participation and loneliness

As described in the first chapter, participation was defined as 'involvement in life situations' [7]. The ICF offers a taxonomy for the domain of 'Activities and Participation' with nine chapters and gives several options to differentiate 'participation' from 'activities'. In this thesis, the method of Post et al. [8] was applied which designates four ICF-chapters that represent participation: (1) domestic life; (2) interpersonal interactions and relationships; (3) major life areas; and (4) community, social and civic life. To facilitate comparison in participation between the visually impaired elderly and the reference population, we

measured self-reported performance of participation in a similar method as the population surveys [3-6,9]. Each ICF participation chapter was linked to suitable items of these population surveys, which subsequently were included in the interview schedule.

Participation in domestic life (*ICF-chapter 6)* included light household activities, heavy household activities, assisting others and shopping. Interpersonal interactions and relationships (*ICF-chapter 7)* were operationalized as socializing. This was defined as meeting relatives, friends and neighbors in person, including contact by telephone or e-mail. Major life areas (*ICF-chapter 8)* comprised paid work and voluntary work. The community, social and civic life chapter (*ICF-chapter 9)* included involvement in clubs or associations; going out to recreational places for entertainment, and going out to cultural places and public places; going on holidays; involvement in hobby activities, sports activities and religious activities.

In addition to self-reported performance of participation, participation restrictions were assessed. Participants rated to what extent their participation in these four domains of participation was restricted due to the visual impairment.

Loneliness is a situation experienced by an individual, where there is an unpleasant or inadmissible lack of (quality of) certain relationships, and was assessed with the 11-item Loneliness Scale of De Jong Gierveld [10,11].

2.2.4 Determinants of participation and loneliness

In this thesis, a biopsychosocial model was used to investigate factors that influence the level of participation and loneliness among the visually impaired elderly. In addition to sociodemographic characteristics (i.e., age, gender, educational level, and income), the physical health status, social and psychological status were assessed. Physical health status included vision-related variables (i.e., self-perceived vision, duration of vision loss, and degree of visual impairment as indicated by corrected binocular visual acuity at distance [VODS]) and health-related variables (i.e., general health perceptions, fatigue, perceived physical fitness and co-morbidity). Social status variables comprised partner status, social network size and negative social support. Psychological status variables included mental health, helplessness, self-esteem, and the self-management abilities 'self-efficacy' and 'taking initiatives'. An additional factor that was included in the analyses of participation considered the personal values that visually impaired elderly persons attach to participation, operationalized as perceived importance of specific aspects of participation. Table 2.1 gives an overview of the measurement instruments that were included in the survey study.

Table 2.1: Overview of the determinants and the instruments used in the survey study

Variable	Measurement instrument	Reference	Number of items	Score
Sociodemographic				
- Age	Date of birth	NA	1	-
- Gender	-	NA	1	-
- Educational level	International Standard Classification of Education (ISCED)	[28]	1	0-4
- Income	Self-reported income in categories ranging from <1000€ a month to ≥3000€ a month	NA	1	0-5
Physical health status				
a. Vision-related				
- Self-perceived vision	General vision subscale of the Visual Functioning Questionnaire (VFQ-25)	[29]	1	0-100
- Duration of vision loss	Self-reported age of onset of vision loss related to participant's age	NA	1	-
- Degree of VI	logMAR value (-log visual acuity)	NA	-	-
b. Health-related				
- General health perceptions	General health perceptions subscale of the RAND-36	[25,26]	5	0-100
- Fatigue	General fatigue subscale of the Multidimensional Fatigue Inventory (MFI)	[30]	4	4-20
- Perceived physical fitness	Perceived fitness subscale of the Groningen Fitness test for the Elderly (GFE)	[31]	10	10-50
- Co-morbidity	Number of self-reported chronic conditions	NA	1	-
Social status				
- Partner status	Self-reported partner status (having a partner of being single)	NA	1	-
- Social network size	Number of individuals within network of children, relatives, friend and neighbors	NA	4	-
- Negative social support	Negative interactions subscale of the Social Support List (SSL)	[32]	7	7-28
Psychological status				
- Mental health	Mental health subscale of the RAND-36	[25,26]	5	0-100
- Helplessness	Helplessness subscale of the Illness Cognition Questionnaire (ICQ)	[23]	6	6-24
- Self-esteem	Rosenberg Self-esteem scale	[33]	10	10-40
- SMA self-efficacy	Self-efficacy subscale of the Self-Management Ability Scale (SMAS-30, version 1)	[24]	5	5-30
- SMA taking initiatives	Taking initiatives subscale of the SMAS-30	[24]	5	5-30

NA Not available; *VI* Visual Impairment; *SMA* Self-management ability

2.3 Intervention study

2.3.1 Development of the Visually Impaired elderly Persons Participating program

In order to enhance participation in society of the visually impaired elderly, we developed the multidisciplinary group rehabilitation program *Visually Impaired elderly Persons Participating (VIPP)*. In Dutch, this program is entitled *ACTIEF MEEDOEN*. Within this thesis, the acronym *VIPP* will be used to refer to this multidisciplinary group rehabilitation program.

The *VIPP*-program was developed according to the principles of intervention mapping, which is a stepwise procedure for developing theory-, evidence- and practice-based interventions [12,13]. The results of the survey study on the determinants of participation were used to develop the *VIPP*-program. Furthermore, we performed two focus group interviews with the target population of visually impaired elderly persons (n=8 and n=9) and a focus group interview with delegates of interest groups for blind and visually impaired people (n=7). The aim of these focus group interviews was to gain more in-depth knowledge on determinants of participation among the visually impaired elderly. In addition, we organized an expert meeting with health professionals involved in low-vision rehabilitation, researchers and visually impaired elderly persons (n=9). Finally, we reviewed the literature on determinants of participation and existing low-vision rehabilitation interventions. The results of the survey study, the focus group interviews, the expert meeting and the literature search guided the development and design of the *VIPP*-program. The physical therapist, occupational therapists, social workers and the management team of Visio were involved in developing the *VIPP*-program. First, a broad outline of the program was developed in close cooperation with the representatives of the different disciplines involved. Next, the detailed content of the group sessions was determined by means of subgroups of all supervisors involved in performing the program. Subsequently, in extensive consultation with the professionals of Visio a program manual was written.

The *VIPP*-program aims to enhance participation in society by improving practical skills, promoting adaptation to the visual impairment, and improving physical fitness. Therefore, the *VIPP*-program consists of four components: (1) training of practical skills; (2) education, social interaction, and counseling and training of problem-solving skills; (3) individual and group goal-setting; and (4) a home-based physical exercise program. It is a 20-week program that consists of structured group sessions of 2 hours and a booster session 12 weeks after the completion of the program. Each session starts with 60 minutes of practical training by two occupational therapists. After a 15-minute break, the social worker continues with a 45-minute education and counseling session. During the first session, an exercise coach introduces simple physical exercises and a graded walking program. Additionally, the exercise coach delivers counseling by means of 12 telephone conversations throughout the program according to the principles of motivational interviewing [14,15]. The progress, benefits and

difficulties of physical activity as perceived by the study participants are being discussed. Table 2.2 gives a short overview of the topics within each of the four components.

All sessions were conducted in small interactive groups that contained sufficient participants to enable social interaction but had a maximum of nine participants to ensure safety within the practical training component. Because of the relatively long duration of the *VIPP*-program and the potential problems with transport, we aimed to deliver the program within the vicinity of the study participants, i.e., at two locations of Visio (Haren and Leeuwarden) as well as at two rural locations in the northern part of The Netherlands (Drachten and Emmen). This resulted in a group size that varied from 4 to 9 participants. All supervisors of the program were trained before the start of the intervention.

2.3.2 Study participants and study design

Participants of this intervention study originated from the survey study. Additional inclusion criteria for the intervention study were: (1) having a low level of outdoor participation; and (2) being able to walk (with or without a walking aid). Of the 173 participants of the survey study, 134 were eligible for the intervention study. Those 134 participants received information about the *VIPP*-program by mail in November 2008. By returning a reply card, participants could indicate whether they were interested to cooperate. Those who did not respond within three weeks received a reminder phone call. Forty-three visually impaired elderly (32%) were interested and received detailed information about the *VIPP*-program. Twenty-nine persons (22%) gave informed consent of which 26 (90%) completed the whole intervention program. Figure 2.2 shows a flow diagram of the inclusion of the study participants.

The effect of the *VIPP*-program was tested in a pilot study with a single group pre-test post-test design. Data were collected at baseline (pre-test, January 2009), halfway through the intervention (April 2009), immediately after the intervention (post-test, July 2009) and six months later (long-term follow-up, December 2009). Data with respect to the primary outcome measure participation and the secondary outcome measure psychosocial functioning were collected by means of face-to-face interviews performed by experienced interviewers. In addition to these face-to-face interviews, data with respect to the physical functioning as a secondary outcome measure were collected by field-based assessments of physical fitness. Participation was assessed at baseline, post-test and at long-term follow-up. The secondary outcome measures psychosocial and physical functioning were assessed at baseline, half-way through the intervention, at post-test and at long-term follow-up.

Table 2.2: Short overview of the topics within each of the four components of the multidisciplinary group rehabilitation program *VIPP*

Training of practical skills	**Education, social interaction, and counseling and training of problem-solving skills**	**Individual and group goal-setting**	**Home-based physical exercise program**
Orientation and mobility (O&M): - aids and devices for O&M - O&M in and around home - O&M as a pedestrian - using public transport - finding your way in public areas/ buildings - compensatory use of other senses *Participation:* - shopping - leisure and recreation	*Education:* - basic anatomical structures of eye and eye diseases - services and supports available for visually impaired people *Social interaction:* - sharing experiences: ▪ emotional impact (dependency, society's expectations) ▪ coping strategies *Counseling and training of problem-solving skills:* - asking for assistance - explaining vision loss to others - recognizing body language and communication with others - energy balance	*Goal-setting and action planning* *Individual:* - identifying personal goals - making an action plan - feedback on action plan and discussing progress - examples: ▪ using public transport ▪ visiting a concert/museum ▪ joining a fitness club ▪ shopping independently *Identifying group goals:* - examples: ▪ fall prevention ▪ visiting a fitness club ▪ playing card and board games ▪ making a forest walk	*Home based physical exercise:* - graded step-by-step walking program - physical exercises 3x per week *Telephone counseling by exercise coach:* - 12 scheduled conversations - evaluating progress walking program and physical exercises - discussing benefits of being physically active - discussing barriers and perceived difficulties

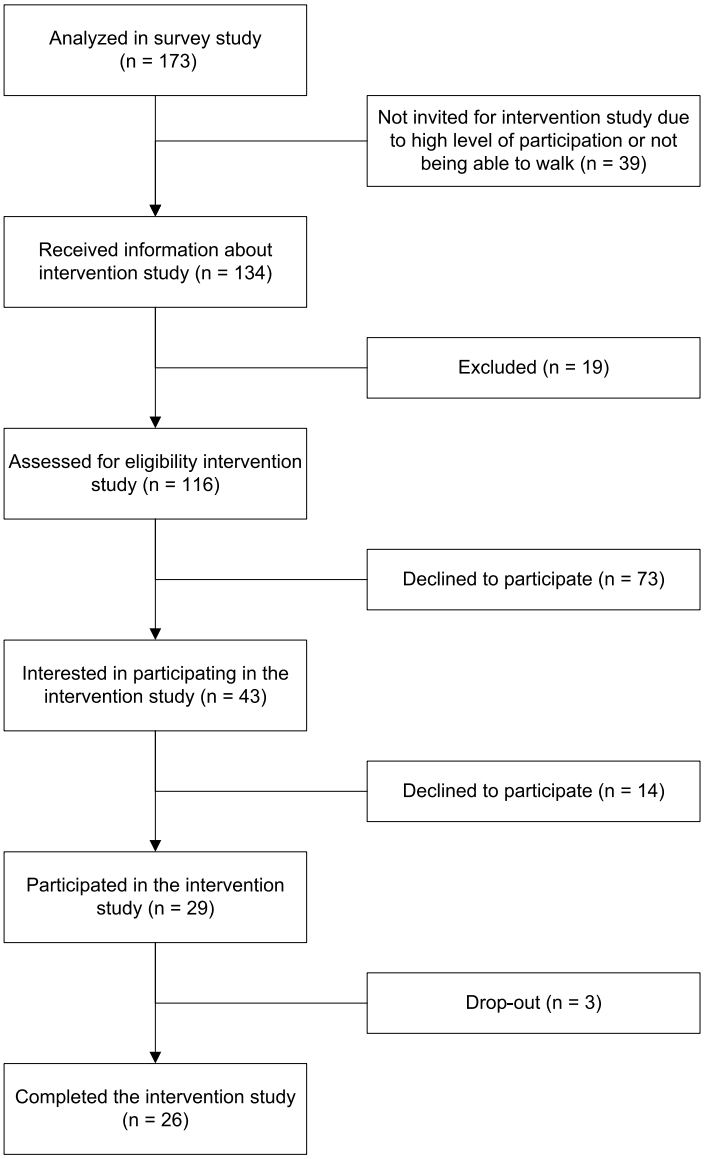

Figure 2.2: Flow diagram of inclusion of the study participants in the intervention study

Table 2.3: Overview of the variables and measurement instruments used in the intervention study

Variable	Measure instrument	Reference	Number of items	Score
Participation				
- Frequency	Frequency subscale of the Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P)	[17]	12	0-100
- Restrictions	Restrictions subscale of the USER-P	[17]	10	0-100
- Satisfaction	Satisfaction subscale of the USER-P	[17]	6	0-100
- Autonomy outdoors	Autonomy outdoors subscale of the Impact on Participation and Autonomy (IPA)	[18,19]	5	0-4
Physical functioning				
- Aerobic endurance	2-minutes Step Test	[20]	-	-
- Functional mobility	Timed Up and Go test (TUG)	[20]	-	-
Psychosocial functioning				
- Adaptation to vision loss	Dutch version of Adaptation to age-related Vision Loss (N-AVL-12)	[21,22]	12	0-36
- Helplessness	Helplessness subscale of the Illness Cognition Questionnaire (ICQ)	[23]	6	6-24
- Self-efficacy	Self-efficacy subscale of the Self-Management Ability Scale (SMAS-30, version 1)	[24]	5	5-30
- Mental health	Mental health subscale of the RAND-36	[25,26]	5	0-100
- Fear of falling				
- Generic	Falls-Efficacy Scale (FES)	[27]	16	16-64
- Vision-specific	Selection of vision-specific items	[27,28]	6	6-24

2.3.3 Outcome measures

Since the *VIPP*-program aims to enhance participation by improving practical skills, promoting adaptation to the visual impairment and improving physical fitness, we distinguished primary and secondary outcome measures. Participation was the primary outcome measure whereas physical and psychosocial functioning were included as secondary outcome measures. Table 2.3 gives an overview of the measurement instruments used to assess the primary and secondary outcomes of the intervention study, which will be described in more detail in the next three paragraphs.

Primary outcome measure: participation

For the intervention study, we used a newly developed participation measurement instrument: the Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P) [16]. The USER-P is based on the ICF and assesses three aspects of participation (i.e., performance frequency, restrictions and satisfaction) and covers vocational activities, leisure activities and social activities. The frequency subscale assesses the number of hours weekly spend on vocational activities as well as the frequency of performing leisure and social activities. The restriction subscale assesses perceived restrictions due to the health condition (i.e., visual impairment). Lastly, the satisfaction subscale asks persons to rate their satisfaction with participation. For this study, the satisfaction subscale was based only on the items that addressed participation according to the definition used in this thesis. In addition, a fourth aspect of participation (i.e., autonomy outdoors) was assessed by the outdoors subscale of the Impact on Participation and Autonomy questionnaire (IPA) [17,18].

Secondary outcome measure: physical functioning

To test the effect of the *VIPP*-program on physical functioning, two aspects of physical fitness were used: aerobic endurance and functional mobility. Aerobic endurance was assessed with the 2-minutes step test [19] while the Timed Up and Go test [19] was used to assess functional mobility.

Secondary outcome measure: psychosocial functioning

To test the effect of the *VIPP*-program on psychosocial functioning, five indicators of psychosocial functioning were used: adaptation to vision loss, helplessness, self-efficacy, mental health and fear of falling. Adaptation to vision loss was assessed with the Dutch version of the Adaptation to age-related Vision Loss scale -12 item version (N-AVL-12) [20,21], which is a measure of psychosocial adjustment specifically developed for older adults who need to adapt to late-life vision loss. Helplessness refers to an attributional style explaining negative events, such as vision loss, and its consequences as uncontrollable, unpredictable and unchangeable. The Illness Cognition Questionnaire (ICQ) [22] was used

to assess helplessness. The Self-Management Ability Scale-30 (SMAS-30, version 1) [23] was used to assess the self-management ability self-efficacy, which refers to the ability to gain and maintain a belief in a person's competence. Mental health was assessed with a subscale of the RAND-36 [24,25], which assesses feelings of depression and nervousness. Lastly, two aspects of fear of falling were included: generic and vision-specific fear of falling. The Falls-Efficacy Scale (FES) [26] was used to assess the level of concern about falling when performing physical activities, social activities, and mobility activities. In addition, vision-specific fear of falling was measured with six items, based on a study of Marquant [27], that assessed the level of fear of falling when using public transport, crossing the street, walking up and down steps, walking in an area with many obstacles, walking in heavy traffic, and walking in a noisy area.

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3

Participation of the elderly after vision loss

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Abstract

Purpose. To assess the degree of participation of the visually impaired elderly and to make a comparison with population-based reference data.

Method. This cross-sectional study included visually impaired elderly persons (≥55 years; *n*=173) who were referred to a low-vision rehabilitation centre. Based on the International Classification of Functioning, Disability and Health (ICF) participation in: (1) domestic life, (2) interpersonal interactions and relationships, (3) major life areas, and (4) community, social and civic life was assessed by means of telephone interviews. In addition, we assessed perceived participation restrictions.

Results. Comparison with reference data of the elderly showed that visually impaired elderly persons participated less in heavy household activities, recreational activities and sports activities. No differences were found for the interpersonal interactions and relationships domain. Participants experienced restrictions in household activities (84%), socializing (53%), paid or voluntary work (92%), and leisure activities (88%).

Conclusions. Visually impaired elderly persons participate in society, but they participate less than their peers. They experience restrictions as a result of vision loss. These findings are relevant, since participation is an indicator for successful aging and has a positive influence on health and subjective well-being.

3.1 Introduction

Above the age of 50 the prevalence of visual impairment increases exponentially [1]. A recent study in The Netherlands has reported prevalence rates in 2008 of 2.4% for blindness (visual acuity < 0.05) and 7.8% for low vision (0.05 ≤ visual acuity < 0.3) in the elderly aged 65 and over [2]. The majority (79%) of the total number of visually impaired people (visual acuity < 0.3) is 65 years or older [2]. Due to the aging of the population the number of visually impaired elderly persons will strongly increase over the decades to come [1,3]. In the Netherlands, it is estimated that between 2005 and 2020 the number of visually impaired elderly persons will increase by 18.7% [1]. Visually impaired elderly persons will be doubly burdened; next to the general consequences of aging, they will experience additional restrictions due to the visual impairment [4], which is a potential threat to maintaining independence in daily life.

In general, activity and time-spending patterns change when people grow older [5-8]. Older individuals have more difficulty performing daily activities and perceive more participation restrictions in daily life such as mobility outside the home and interpersonal interactions [9]. From age 75, participation decreases strongly [10]. In addition to the effect of aging, vision loss may not only lead to difficulties in performing activities [11-17] but also to loss of activities [18,19], dependency [20-22] and social isolation [23]. Vision loss is related to depression [24-27] and emotional distress [28] and has a negative impact on health-related quality of life [15,28-33]. Besides, it is regarded an important factor of disability [23].

According to the International Classification of Functioning, Disability and Health (ICF) [34] of the World Health Organization (WHO), an individual's functioning or disability is a dynamic interaction between health conditions and contextual factors (i.e. environmental and personal factors). With the ICF, the WHO underlines the importance of participation – defined as 'involvement in life situations' – as an outcome measure of health condition. Previous research among the visually impaired elderly mostly focused on limitations in executing activities, such as reading, community, mobility and self-care [11-16,35-38]. A recent study on participation restrictions of visually impaired elderly persons showed that they experienced more problems compared to the elderly without visual impairment [39]. To the best of our knowledge, self-reported performance of participation of visually impaired elderly persons has not been extensively investigated. In accordance with the policy of the WHO, as described in the ICF, our study focuses on participation in society of the visually impaired elderly.

The present study aims to describe the degree of participation of visually impaired elderly persons and to make a comparison with population-based reference data of the elderly. In addition, we examine differences in participation between relatively younger and

older participants, and between those with relatively better and those with poor vision. Based on the literature, we expect that the visually impaired elderly participate less than the elderly in the reference population. Likewise, we expect that older participants participate less than younger participants, and that participants with poor vision participate less than participants with better vision. Besides self-reported performance of participation, this study also assesses perceived participation restrictions. We expect that older participants and participants with poor vision perceive more restrictions.

3.2 Methods

3.2.1 Study population

An age-stratified sample of 350 visually impaired elderly persons was drawn out of all 786 newly registered visually impaired elderly persons (≥ 55 years) at Royal Dutch Visio (region North Netherlands), a low-vision rehabilitation provider, between 1 July 2006 and 30 June 2007. Stratification was applied (i.e. < 75 years vs. ≥ 75 years) because of expected differences in participation between these age groups. Inclusion criteria were: (1) aged ≥ 55 years; (2) able to speak Dutch; (3) able to understand instructions concerning response sets; and (4) referred to a low-vision rehabilitation centre according to the 'Guidelines on the referral of visually impaired persons to low-vision services' [40]. According to these evidence-based guidelines of the Dutch Society of Ophthalmology, persons with a visual acuity < 0.3 and/or visual field < 30 degrees in the better eye should be referred for rehabilitation to a low-vision rehabilitation centre. In addition, persons with a visual acuity < 0.5 who experience problems with reading or other daily life activities due to visual impairment and who have a well-defined request for help should be referred to a low-vision rehabilitation centre as well. Out of the sample, 264 persons were eligible for participation in the study and 173 persons agreed to participate (response 66%). Figure 3.1 shows a flow diagram of inclusion of study participants. Non-response analysis showed that study participants (mean age 72.3 years; SD 9.7) were younger than non-responders (mean age 78.5 years; SD 9.7; $t = -4.976$, $p < 0.001$). No difference was found with respect to gender.

3.2.2 Design and procedure

Data for this cross-sectional study were collected by means of telephone interviews performed by experienced interviewers who received an additional training. We performed seven pilot interviews to test the interview schedule, which resulted in a minor revision of the interview schedule. Prior to the telephone interview participants gave informed consent. The study design was reviewed by the Medical Ethics Review Committee of the University Medical Center Groningen. The study followed the tenets of the Declaration of Helsinki.

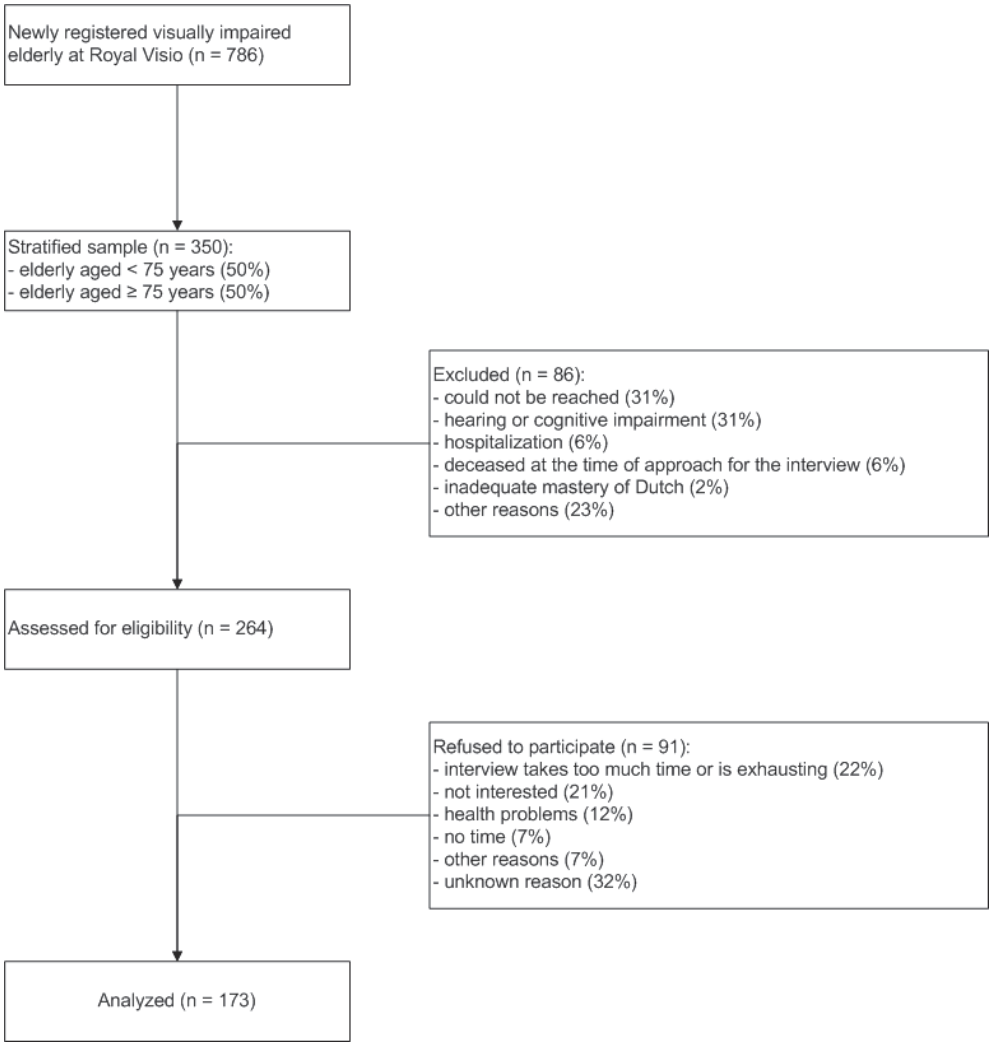

Figure 3.1: Flow diagram of inclusion of the study participant

3.2.3 Measures

Self-reported performance of participation.

In accordance with the ICF, participation was defined as 'involvement in life situations' [34]. The ICF lists nine chapters that cover the full range of 'Activities and Participation' [34] and gives several options for differentiating 'Participation' from 'Activities'. We adopted the method of Post et al. [41] that applied one of these options, and designated four chapters that represent participation: (1) domestic life (ICF-chapter 6); (2) interpersonal interactions

and relationships (ICF-chapter 7); (3) major life areas (ICF-chapter 8); and (4) community, social and civic life (ICF-chapter 9).

To enable the comparison in degree of participation between visually impaired elderly persons and population-based reference data, we measured participation in a similar method as the population surveys that generated these reference data [42-44]. For this purpose, each of the four ICF-chapters was linked to suitable survey items, which subsequently were included in the interview schedule. Two items that were not listed in the surveys (i.e. going shopping and hobby activities) were additionally included, because of their relevance to the population under study.

Participation in *domestic life* (ICF-chapter 6) comprised light household activities (e.g. doing the dishes, dusting, ironing, and cooking), heavy household activities (e.g. window cleaning, vacuuming, and mopping), assisting others (i.e. informal assistance of others outside the respondent's own home), and shopping (alone or with someone else). Performance of these activities was assessed as a dichotomous variable (yes/no). *Interpersonal interactions and relationships* (ICF-chapter 7) were operationalised as socializing, defined as meeting relatives, friends, or neighbours in person, including contact by telephone or e-mail. Elderly persons who socialized once a week or more were classified as frequently participating (yes/no). *Major life areas* (ICF-chapter 8) comprised paid work and voluntary work. Because in the Netherlands official retirement starts at the age of 65, participation in employment and weekly working hours were only assessed in participants aged <65 years. Employment (yes/no) was defined as participation in paid work irrespective of the number of hours spent per week. Voluntary work (yes/no) was defined as unpaid work in organized associations. The *community, social and civic life* (ICF-chapter 9) domain comprised involvement in clubs or associations (yes/no), in hobby activities (yes if ≥1x/week); going out to recreational places for entertainment (e.g. nature reserve, forest, public garden, recreation area; yes if ≥1x/month), cultural places (e.g. theatre, cinema, museum; yes if ≥1x/month) and public places (e.g. café or restaurant; yes if ≥1x/month); going on holidays (yes if ≥1x/year); involvement in sports activities (yes/no); and in religious activities (yes if ≥1x/month).

Perceived participation restrictions.

Perceived restrictions in participation were assessed by four questions constructed by the authors. Participants rated to what extent their participation in household activities (ICF-chapter 6), socializing (ICF-chapter 7), paid or voluntary work (ICF-chapter 8), and leisure activities (ICF-chapter 9) is restricted due to the visual impairment. The response set consisted of a 4-point scale: not at all, a little, quite a bit, very much. Participants with score 1 (not at all) were classified as experiencing no participation restrictions, whereas participants with score 2 through 4 were classified as experiencing restrictions.

Vision-related characteristics.

(a) Degree of visual impairment was indicated by corrected binocular visual acuity at distance (VODS). Data with respect to visual acuity and vision impairment were collected from medical files available at the low-vision rehabilitation centres of Royal Dutch Visio, such as the referral form of the treating ophthalmologist of the hospital. If this referral form was unavailable, the most recent report of the optometrist of Royal Dutch Visio was used. *(b) Duration of vision loss* was computed by subtracting self-reported age of onset of vision loss from participants' age. *(c) Self-perceived vision* was measured with the single-item subscale 'general vision' of the Visual Functioning Questionnaire (VFQ-25) [45]. Participants were asked: 'At the present time, would you say your eyesight using both eyes (with glasses or contact lenses) is excellent, good, fair, poor, very poor or are you completely blind?' Participants with response categories excellent through fair were classified as having relatively 'better vision', whereas participants with responses poor through completely blind were classified as having 'poor vision'. Stratification of vision was based on self-perceived vision (VFQ-25) because of the heterogeneity of visual impairment in the study group. According to the Dutch guidelines [40] not only persons with loss of visual acuity were referred to Royal Dutch Visio, but persons with a visual field defect and persons who experienced problems with reading or other daily life activities were referred as well and subsequently included in our study.

Demographic characteristics and co-morbidity.

The following demographic characteristics were assessed: age, gender, and living arrangement (living alone vs. co-residing). Co-morbidity was measured by means of an open-ended question that asked participants to list all chronic conditions they were suffering from other than their eye disease. The number of chronic conditions was used as a co-morbidity variable.

3.2.4 Statistical analysis

Non-response analysis was performed with Student's *t* test and Chi-square test. Data on participation of study participants were compared with reference data from Statistics Netherlands [10] and the Longitudinal Ageing Study Amsterdam (LASA) [46]. Because Statistics Netherlands presents data stratified for three age groups, we stratified for age in the same way: (1) 55 - 64 years; (2) 65 - 74 years; and (3) ≥75 years. Differences in participation were tested with Chi-square tests.

To analyse differences in participation related to age and vision, we accordingly stratified the study group for age (<75 years [*n* = 103] vs. ≥75 years [*n* = 70]) and vision ('poor vision' [*n* = 118] vs. 'better vision' [*n* = 48]). Differences between these subgroups were tested with Chi-square tests. Fisher's exact test (one-sided) was used when expected frequencies in

crosstab tabulation were less than 5.
Due to multiple comparisons, which give a higher probability of finding a statistical significant difference just by chance, a stricter cut-off for statistical significance was applied (p <0.01). In accordance with our formulated expectations one-sided tests were used. All analyses were performed with the statistical software package SPSS, version 14.0 (SPSS, Inc., Chicago).

3.3 Results

3.3.1 Study population
Table 3.1 shows the demographic and vision-related characteristics of the study group. Participants' ages ranged from 55 to 93 years (mean age 72 years). Sixty percent were aged <75 years. Median time since onset of vision loss was 7 years (range 0-75 years). Seventy-one percent of the participants had poor vision and 29% had better vision. The median binocular visual acuity was 0.25. The binocular visual acuity ranged from 0.001 to 1.25 (20/20000 - 20/16). Five percent of the participants were blind (VODS <0.05). Age-related maculopathy was the most common primary cause of the visual impairment (49%). More than half of the participants (55%) had one or more chronic conditions other than their eye disease (range 0-5; median = 1). Diseases of the circulatory system (18%) and diabetes mellitus (12%) were the most prevalent chronic conditions participants were suffering from.

3.3.2 Self-reported performance of participation
The majority of the participants in the study group performed light household activities, went shopping, and was involved in socializing with family members, friends and neighbours (Table 3.2). Of the participants of working age (<65 years) 33% had a paid job (mean 31.1 hrs/week; SD 12.0; range 5-48). Work disability due to vision loss was cited by 63% of the unemployed as the main reason for not being employed. With respect to participation in the community, social and civic life, the majority of participants (77%) were involved in hobby activities, whereas a minority of the participants reported going out to recreational (23%), public (16%) and cultural places (4%).

Table 3.1: Demographic and vision-related characteristics, and co-morbidity of the study group (*n* = 173)

Characteristic	Value, *n* (%)[a]
Age (years)	
55-64	40 (23)
65-74	63 (36)
75-84	51 (30)
≥ 85	19 (11)
Mean ± SD	72.3 ± 9.7
Sex	
Male	73 (42)
Female	100 (58)
Living arrangement	
Alone	77 (45)
Co-residing	96 (55)
Duration of vision loss (years)	
Median	7
Self-reported general vision (VFQ-25)	
Poor vision	118 (71)
Better vision	48 (29)
Binocular visual acuity at distance (VODS)	
Median	0.25
Primary cause of visual impairment	
Age-related maculopathy	81 (49)
Vascular disorders[b]	12 (7)
Optic nerve disorders	10 (6)
Congenital and hereditary disorders[c]	7 (4)
Corneal disorders	5 (3)
Glaucoma	4 (2)
Cataract	4 (2)
Other primary causes	12 (7)
Combination of causes	22 (13)
Cause unknown	10 (6)
Co-morbidity	
0	74 (45)
1	56 (34)
≥ 2	35 (21)
Type of co-morbid diseases	
Diseases of the circulatory system	29 (18)
Diseases of the respiratory system	11 (7)
Diseases of the nervous system	9 (5)
Diseases of the vestibular system	8 (5)
Diabetes mellitus	19 (12)
Osteoarthritis	11 (7)
Rheumatoid arthritis	8 (5)
Other chronic conditions	45 (27)

[a] Percentages are based on totals for each category, and may not total 100 because of rounding
[b] e.g. diabetic retinopathy
[c] e.g. retinitis pigmentosa

Table 3.2: Self-reported performance of participation of visually impaired elderly persons (*n* = 173)

Domain of participation	Value, *n* (%)
Domestic life	
Light household activities	155 (90)
Heavy household activities	74 (43)
Assisting others	70 (40)
Go shopping	148 (86)
Interpersonal interactions and relationships	
Socializing with relatives[a]	152 (88)
Socializing with friends[a]	131 (76)
Socializing with neighbours[a]	120 (69)
Major life areas	
Employment (n = 40, < 65 years)	13 (33)
Voluntary work	47 (27)
Community, social and civic life	
Involvement in clubs/associations	87 (50)
Hobby activities[a]	133 (77)
Recreational places[b]	39 (23)
Cultural places[b]	7 (4)
Public places[b]	28 (16)
Holidays[c]	99 (57)
Sports activities	70 (40)
Walking	22 (31)
Cycling	11 (16)
Gymnastics	10 (14)
Swimming	5 (7)
Other	22 (31)
Religious activities[b]	54 (31)

[a] ≥ 1x/week
[b] ≥ 1x/month
[c] ≥ 1x/year

3.3.3 Comparison with population-based reference data

Comparison with population-based reference data (Table 3.3) showed that visually impaired elderly persons in all age groups participated less in heavy household activities (p <0.001 for all age groups). In addition, visually impaired participants aged 55-64 years and aged 65-74 years went less often to recreational places (p <0.001 for both age groups) and participated less in sports activities (p = 0.004 and p <0.001 respectively) compared with their peers. However, visually impaired participants aged ≥75 years were more involved in assisting others (p <0.001) compared with their peers. No differences were found for the domain of interpersonal interactions and relationships, and the domain of major life areas.

Table 3.3: Comparison of self-reported performance of participation of visually impaired elderly persons with a reference population of elderly, stratified for age

	Age 55-64 years			Age 65-74 years			Age ≥75 years		
	Study group	Reference population		Study group	Reference population		Study group	Reference population	
Domain of participation	***n* = 40**	***n* = 1113**	***P***	***n* = 63**	***n* = 713**	***P***	***n* = 70**	***n* = 575**	***p***
Domestic life									
Light household activities	97	93[e]	0.14	91	95[e]	0.06	84	93[e]	0.01
Heavy household activities	63	90[e]	< 0.001	52	84[e]	< 0.001	23	55[e]	< 0.001
Assisting others	50	33	0.01	41	34	0.12	34	18	< 0.001
Interpersonal interactions and relationships									
Socializing with relatives[a]	83	87	0.20	89	86	0.26	90	88	0.31
Socializing with friends[a]	83	73	0.09	73	73	0.50	74	70	0.23
Socializing with neighbours[a]	68	75	0.14	68	80	0.02	71	70	0.41
Major life areas									
Employment	33	47	0.04	-[d]	-[d]	-[d]	-[d]	-[d]	-[d]
Voluntary work	33	41	0.14	33	46	0.03	19	26	0.09
Community, social and civic life									
Involvement in clubs/associations	45	41	0.31	57	46	0.04	47	36	0.03
Recreational places[b]	18	59	< 0.001	24	54	<0 .001	24	34	0.05
Public places[b]	25	32	0.18	13	26	0.01	14	18	0.22
Holidays[c]	73	77	0.25	60	65	0.23	46	41	0.23
Sports activities	50	71[e]	0.004	35	69[e]	< 0.001	40	51[e]	0.05
Religious activities[b]	20	20	0.50	37	33	0.28	33	34	0.42

Data are given as percentage of participants; reference data are extracted from Statistics Netherlands [10] unless otherwise indicated

[a] ≥ 1x/week

[b] ≥ 1x/month

[c] ≥ 1x/year

[d] Because 65 is the age at which official retirement starts in the Netherlands, no data are available for these age groups

[e] Reference data extracted from LASA [46]: age 55-64 years (*n* = 374); age 65-74 years (*n* = 379); age ≥ 75 years (*n* = 234)

Table 3.4: Differences in self-reported performance of participation between subgroups, stratified for age and self-reported general vision (*n* = 173)

Domain of participation	Age < 75 years *n* = 103	Age ≥ 75 years *n* = 70	*p* value	Better vision *n* = 48	Poor vision *n* = 118	*p* value
Domestic life						
Light household activities	93	84	0.03	90	90	0.58[e]
Heavy household activities	56	23	< 0.001	50	42	0.16
Assisting others	45	34	0.09	44	39	0.29
Go shopping	88	81	0.10	88	86	0.37
Interpersonal interactions and relationships						
Socializing with relatives[a]	86	90	0.23	85	89	0.26
Socializing with friends[a]	77	74	0.36	75	76	0.43
Socializing with neighbours[a]	68	71	0.31	79	64	0.03
Major life areas						
Employment	-[d]	-[d]	-[d]	42[f]	29[f]	0.33[e]
Voluntary work	33	19	0.02	33	25	0.15
Community, social and civic life						
Involvement in clubs/associations	52	47	0.25	54	47	0.19
Hobby activities[a]	85	66	0.002	88	74	0.03
Recreational places[b]	21	24	0.33	23	23	0.50
Cultural places[b]	4	4	0.59[e]	8	3	0.11[e]
Public places[b]	18	14	0.29	21	15	0.19
Holidays[c]	65	46	0.006	59	58	0.47
Sports activities	41	40	0.46	50	37	0.07
Religious activities[b]	30	33	0.35	35	28	0.17

Data are given as percentage of participants
[a] ≥ 1x/week
[b] ≥ 1x/month
[c] ≥ 1x/year
[d] Because 65 is the age at which official retirement starts in the Netherlands, the difference in employment between the two age groups was not tested
[e] Fisher's exact test
[f] This item only applied to participants aged < 65 years (*n* = 40); better vision (*n* = 12); poor vision (*n* = 28)

Table 3.5: Perceived participation restrictions and differences in participation restrictions between subgroups, stratified for age and self-reported general vision (*n* = 173)

Domain of participation	Study group *n* = 173	Age < 75 years *n* = 103	Age ≥ 75 years *n* = 70	*p* value	Better vision *n* = 48	Poor vision *n* = 118	*p* value
Household activities	84	84	83	0.43	65	92	<0 .001
Socializing	53	52	54	0.41	35	60	0.002
Paid or voluntary work[b]	92	95	84	0.26[a]	94	91	0.56[a]
Leisure activities	86	84	89	0.18	79	89	0.05

Data are given as percentage of participants

[a] Fisher's exact test

[b] This item only applied to participants having paid work and/or voluntary work (*n* = 51)

3.3.4 Differences in participation between subgroups

Differences in participation between younger and older participants, and differences between participants with better vision and participants with poor vision were examined by stratifying for age and self-reported general vision (VFQ-25), as presented in Table 3.4. Results indicate that younger participants (<75 years) were more engaged in heavy household activities (p <0.001) and hobby activities (p = 0.002), and had more holidays (p = 0.006) compared to older participants (≥75 years). No differences in degree of self-reported performance of participation were found between participants with poor vision and participants with relatively better vision.

3.3.5 Perceived participation restrictions

Table 3.5 presents data on perceived participation restrictions due to visual impairment. The percentage of participants reporting participation restrictions ranged from 53% in socializing to 92% in doing paid or voluntary work. Only 6% of the visually impaired elderly persons indicated not being restricted in any domain of participation. Examination of differences in perceived restrictions between subgroups showed that the prevalence of participation restrictions was highest in the poor vision subgroup. Participants with poor vision perceived more restrictions in household activities (p <0.001) and socializing (p = 0.002) compared to those with relatively better vision. We found no differences in perceived restrictions with respect to age (<75 years vs. ≥75 years).

3.4 Discussion

The objective of this study has been to describe the degree of self-reported performance of participation of visually impaired elderly persons (≥55 years) and to compare this with the degree of participation of a reference population. Results indicate that visually impaired elderly persons do participate in society, i.e. are involved in life situations as defined by the ICF. The majority of our study population was engaged in household activities, in shopping, in socializing with family, friends and neighbours, in hobby activities, and in activities of clubs or associations. Only a minority was engaged in going out to recreational, cultural and public places. Comparison with peers, however, showed that visually impaired elderly persons participated less in household activities and sports activities, and went less often to recreational places, which was in line with our expectations. In contrast, no differences were found for the 'interpersonal interactions and relationships' domain of participation. Besides self-reported performance of participation, we assessed participation restrictions and found that 94% of the visually impaired elderly experienced restrictions in one or more domains of participation.

Studies with respect to self-reported performance of participation among the visually impaired elderly are scarce. To our knowledge only Crews and Campbell [13] assessed participation of American visually impaired elderly persons (≥70 years). With respect to socializing, Crews and Campbell's study found that 74% of the participants visited relatives in the past two weeks, 86% phoned relatives, 67% visited friends and 80% phoned friends [13]. These findings are in line with findings of our study. In contrast, the study of Crews and Campbell reported a higher percentage (56%) of visually impaired elderly persons eating out in a restaurant in the past two weeks [13]. Only 16% of our Dutch study group reported going out to public places (including restaurants) once a month or more. This may be explained by a cultural difference; the general population of the elderly in the United States have more of a habit of eating out in a restaurant than the elderly in the Netherlands (66% [13] vs 22% [10]).

Our study found no differences in the ICF-domain 'interpersonal interactions and relationships' between visually impaired elderly persons and the elderly in the reference population. Socializing, defined as meeting others in person including contact by telephone or e-mail, does not necessarily require elderly persons to go outdoors. Crews and Campbell [13] reported that visually impaired elderly persons were more often engaged in phoning friends (80%) and relatives (86%) than in visiting friends (67%) and relatives (74%). Outdoor mobility restrictions, prevalent in visually impaired elderly persons [47], may be of less influence on this particular domain of participation. However, a study of Boerner et al. [48] showed that 35% of adults with vision impairment perceive a decrease in the frequency of socializing after vision loss and that 47% of visually impaired adults reported being more dependent on others. Wang and Boerner [49] showed that the ways in which visually impaired individuals relate to others changed after vision loss. Visually impaired persons face two major challenges in relating to other people. The first is named 'difficulty in social situations due to a lack of understanding from others'; the second challenge is 'difficulty in social situations due to a lack of visual cues for information' [49]. These challenges indicate re-establishment of ways of communication with other people which was present in 26% of adults with vision impairment [48]. Although we may conclude that there is no difference in the frequency of socializing between the visually impaired elderly and the reference population, Boerner et al. [48] and Wang and Boerner [49] showed that the visually impaired elderly do experience difficulties in socializing.

Besides self-reported performance of participation our study assessed perceived participation restrictions and found high prevalence rates for restrictions in household activities, doing paid or voluntary work and leisure activities. These findings are in line with Lamoureux et al. [11,47] who reported restrictions of visually impaired elderly persons in leisure activities, employment and shopping. Desrosiers et al. [39] showed that compared to the normally sighted elderly, the visually impaired elderly experience more restrictions in

participation in daily activities and social roles. The least restricted domain of participation in our study group was socializing, which corresponds to findings of Lamoureux et al. [11] who report that 44% experienced no restrictions in visiting friends and family due to vision loss, as measured with an item of the consumer and social interactions domain of the Impact of Vision Impairment Questionnaire [50]. Although the visually impaired elderly experience difficulties in socializing [11,48,49], the prevalence of participation restrictions in the domain of interpersonal relationships do not differ from the normally sighted elderly as was shown by Desrosiers et al. [39].

Subgroup analysis showed that the relatively younger study participants (<75 years) participated more in some domains of participation (i.e. heavy household activities, hobby activities, holidays) which is in accordance with our expectations. Those relatively younger study participants, however, experienced the same level of participation restrictions as the older study participants (≥75 years), which was not expected. Although the visually impaired elderly participate less in some domains of participation compared to peers, comparison within the study group showed no differences in self-reported performance of participation between elderly with a poor versus better vision, which contradicts our formulated hypothesis. Apparently, merely having a visual impairment is associated with lower levels of participation, while severity of the visual impairment does not play an additional role. The prevalence of participation restrictions, however, was highest among those with a poor vision, which is in line with findings of Hassell et al. [16], Lamoureux et al. [11,47], and Weih et al. [50]. This finding indicates the negative association between self-reported vision and perceived participation restrictions.

Results of the present study should not be interpreted without taking some limitations into account. The inclusion of study participants through a low-vision rehabilitation centre may implicate selection of a subgroup of the visually impaired elderly. The fact that non-responders were older, may have resulted in an overestimation of participation, because younger study participants had higher levels of participation. In addition, it may be that non-responders were less likely to participate in the study, because they in general are less active. Study participants therefore may have been a select group of relative active visually impaired elderly persons. Furthermore, data on participation were collected by means of subsets of items extracted from available population surveys, which in itself is not equivalent to a validated questionnaire. At the time of the data collection we concluded - based on a review of Perenboom and Chorus [51] and our own literature search - that no participation questionnaire was available that both met our requirements of assessing participation from a comprehensive view, and facilitated comparison with reference populations as well. Data on participation are self-report data derived through telephone interviews which may imply social desirability bias. Lastly, besides age and general vision, other factors prevalent in the visually impaired elderly (i.e. co-morbidity [14,52,53] and depression [24-27,52]) that may

explain differences in participation between the study group and the reference populations could not be examined. Due to unavailability of this information in the reference data sets, it was not possible to test for potential confounding effects.

In conclusion, this study assessed self-reported performance of participation of visually impaired elderly persons from a comprehensive view, based on the ICF-framework of the WHO [34]. We highlighted that visually impaired elderly persons do participate in society, but that in some specific domains they participate less than their peers. In addition, participation restrictions are prevalent in the visually impaired elderly. This is an important finding since participation in society can be considered as an indicator of successful aging [54] and has a positive influence on physical and mental health [55], quality of life [56] and subjective well-being [54]. Decreased participation and activity loss are associated with an increased risk of functional [57] and cognitive decline in the elderly [58,59]. In addition, those who participate less are at risk with regard to social isolation and may experience feelings of loneliness [60].

Visually impaired elderly persons are doubly burdened. Besides the general consequences of aging, they experience additional participation restrictions due to vision loss. The number of elderly people with a visual impairment will increase in the next decades, extending the demand for specialized vision related advice, care and rehabilitation [1]. To guide rehabilitation services, future research is needed to examine which factors (e.g. physical fitness, self-management abilities, self-esteem, social support) determine participation restrictions of the visually impaired elderly.

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4

Determinants of social participation of visually impaired older adults

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ABSTRACT

Purpose. To assess determinants of social participation among visually impaired older adults.

Methods. This cross-sectional study included visually impaired persons (≥55 years; *n* = 173) who were referred to a low-vision rehabilitation center. Determinants (i.e., sociodemographic, physical, social and psychological factors, and personal values) of participation were identified in four domains of participation: (1) domestic life; (2) interpersonal interactions and relationships; (3) major life areas; and (4) community, social and civic life. Study participants completed telephone interviews.

Results. Age, physical fitness, and helplessness were determinants of participation in domestic life. Social network size was associated with participation in major life areas. The personal value attached to participation (i.e., perceived importance) was a determinant of participation in interpersonal interactions and relationships, major life areas, and community, social and civic life. Vision-related characteristics (i.e., self-perceived vision and degree of visual impairment) were not associated with participation.

Conclusions. Across the participation domains, perceived importance is a major determinant of social participation among visually impaired older adults. Physical health along with social and psychological status, also affect participation. Knowing how participation is determined can be used to develop rehabilitation interventions to enhance participation of visually impaired older adults.

4.1 Introduction

Due to aging of the population and the exponential increase in vision loss with increasing age, the number of older adults with a visual impairment is expected to increase [1,2]. Along with the general consequences of aging, these older adults will experience additional restrictions due to vision loss, and as such, they will be doubly burdened [3]. Vision loss may lead not only to limitations in performing activities [4-12], but also to a loss of these activities [13,14], and consequently poses a severe threat to the independence of older adults with a visual impairment.

The concept of participation has become more important since the development of the International Classification of Functioning, Disability, and Health (ICF) by the World Health Organization (WHO) [15]. According to the ICF, participation is defined as "involvement in life situations". The ICF offers a comprehensive model of objective disability outcomes but does not address the subjective perceptions of people with disabilities such as quality of life (QoL) [16]. The WHO, however, does recognize the importance of the QoL concept, as evidenced by their definition of QoL: "the individuals' perception of their position in life in the context of the culture and the value system in which they live and in relation to their goals, expectations, standards and concerns" [17]. With respect to the relationship between participation and QoL, and the available options to include the concept of QoL in the ICF, it is recommended to add QoL as a separate domain to the right of participation [16]. The extent of QoL can be regarded as the ultimate outcome of the disability process [16].

Studies in older adults with and without disabilities showed that participation contributes to QoL [18-20] and is a means of experiencing one's social connection with other people and communities [21]. Participation is also associated with a reduced risk of cognitive [22] and functional decline [23,24]. Therefore, it is important to understand which factors influence the level and the extent of an individual's participation. According to the ICF framework, there is a dynamic interaction between the health condition, contextual factors, such as personal and environmental factors, and participation [15].

With aging, the presence of limitations in physical functioning and participation restrictions increases [25]. Previous research revealed several factors that are associated with participation and participation restrictions. The younger generation of older adults, for example, perceive less restrictions in interpersonal interactions [25] and are more likely to participate in social and leisure activities [26,27]. Other sociodemographic factors, such as income [28] and educational level [29], are associated with participation in voluntary work, and cultural and recreational activities. Older adults with a good health status [30] and those who are physically fit [31] perceive less restrictions in daily activities and are more likely to participate in social activities. Social support from family and friends is a facilitator of participation in society as well [32]. Psychological factors such as emotional distress [33]

and reduced self-efficacy [34,35] are barriers for participation in outdoor activities, social relationships, and work. In addition to these factors, personal expectancies and personal values concerning participation may determine behavior of older adults [36]. Based on this literature, it can be concluded that sociodemographic factors, physical health status, social and psychological status, and personal values affect participation.

Although participation has been studied among older adults in general [25-27,29-32], to our knowledge, only a few studies investigated participation of visually impaired older adults. The results of these studies indicate that reduced distance vision restricts participation in social interactions, daily activities (including household activities), leisure activities, and work [11,37,38]. The perceived quality of distance vision as well as the presence of cardiac disease, and the use of special equipment (e.g., cane, pill dispenser) are associated with reduced participation in self-care, household activities, physical activities, and limitations in mobility [37]. In addition, the physical and mental health of visually impaired older adults affect restrictions in participation [11]. Apart from these studies, there is little available information about the determinants of participation of visually impaired older adults.

The present study aims to investigate factors that influence the level of participation of visually impaired older adults. For this purpose, the impact of various factors will be examined according to the biopsychosocial model. Based on the literature, we expect that sociodemographic variables, physical health status, social status, and psychological status will affect participation. In addition, the effect of the personal values that visually impaired older adults attach to participation will be examined.

4.2 Methods

4.2.1 Study population

A sample of 350 persons was drawn out of the 786 newly registered visually impaired older clients of Royal Dutch Visio (North Netherlands), a low-vision rehabilitation provider, between July 1, 2006, and June 30, 2007. The main inclusion criteria were being aged ≥ 55 years and being referred to a low-vision rehabilitation provider according to the "Guidelines on the referral of visually impaired persons to low-vision services" [39]. According to these evidence-based guidelines, persons with a visual acuity < 0.3 and/or visual field < 30 degrees in the better eye, and persons with a visual acuity < 0.5 who experience problems in daily life should be referred to a low-vision rehabilitation center. From this sample, 264 persons were eligible for this study and 173 persons consented to participate (response 66%). A flow diagram and detailed information about the inclusion procedure are published elsewhere [12]. Non-response analysis showed that study participants (mean age 72.3 [SD 9.7]) were younger than non-respondents (mean age 78.5 [SD 9.7]; t = -4.98, P < 0.001). No difference was found with respect to gender.

4.2.2 Design

Data for this cross-sectional study were collected by means of telephone interviews performed by experienced interviewers. Participants gave informed consent before the interview. The study complied with the Code of Ethics of the Declaration of Helsinki and was reviewed by the Medical Ethics Review Committee of the University Medical Center Groningen.

4.2.3 Measures

Participation

In line with the ICF, we defined participation as "involvement in life situations" [15]. The ICF lists nine chapters that cover the full range of "Activities and Participation" and gives several options for differentiating "Participation" from "Activities". We applied one option, which is in line with Post et al. [40], by identifying four chapters that represent participation: (1) domestic life; (2) interpersonal interactions and relationships; (3) major life areas; and (4) community, social, and civic life. To measure participation, we linked items from available population surveys [41-43] to each of the four ICF chapters and included them in the interview schedule. We performed seven pilot interviews which resulted in minor revisions of the interview schedule.

Participation in domestic life included light household activities, heavy household activities, assisting others, and shopping. Performance of these activities was assessed as a dichotomous variable (yes/no) which was summed to obtain a domestic life participation score (range 0-4).

Interpersonal interactions and relationships were operationalized as socializing, defined as meeting relatives, friends, or neighbors in person (including contact by telephone or e-mail). Persons who socialized once a week or more were classified as frequently socializing (yes/no). The three scores were summed to obtain a participation score for interpersonal interactions and relationships (range 0-3).

Participation in major life areas included participation in voluntary work, defined as doing unpaid work in organized associations and was assessed as a dichotomous variable (yes/no). Since the majority of the study population was retired, we did not assess paid work.

The community, social, and civic life domain included involvement in clubs or associations (yes/no); hobby activities (yes if ≥ 1x/week); sports activities (yes/no); going to recreational places, cultural places and public places (yes if ≥ 1x/month, respectively); going on holidays (yes if ≥ 1x/year); and involvement in religious activities (yes if ≥ 1x/month). The scores for these eight items were summed to obtain a participation score for the community, social, and civic life domain (range 0-8).

Personal values regarding participation were operationalized as the importance of a particular domain, as perceived by the individual, and was assessed with the importance subscale of the participation assessment with recombined tools – satisfaction (PART-S) [44]. Participants rated each domain as being of low, medium, or high importance (score 1-3). The "housekeeping and other activities to keep your home in good order" item was used as an indicator of the importance of participation in domestic life. The mean of the two items "relationships with family and relatives" and "relationships with friends and acquaintances" was used as an indicator of the importance of interpersonal interactions and relationships. The "unpaid work" item covered the importance of participation in major life areas. The mean of the items "participation in religious services", "activities in other organizations", and "recreation and leisure, whether at home or elsewhere" was used as an indicator of the importance of participation in community, social, and civic life.

Sociodemographic characteristics

Age, gender, educational level (based on the International Standard Classification of Education [ISCED] [45]), and income were used as sociodemographic characteristics.

Physical health status

Self-perceived vision was measured by the single-item "general vision" subscale of the visual functioning questionnaire (VFQ-25) [46], which was transformed into a score ranging from 0 to 100 (M=40.1 [SD 18.8]). *Degree of visual impairment*, defined as visual acuity in the better eye, was collected from the medical files available at the low-vision rehabilitation centers of Royal Dutch Visio. Visual acuity values were transformed to logMAR values (-log visual acuity). *Duration of visual impairment* was computed by subtracting the self-reported age of onset of vision loss from a participant's age.

Fatigue was assessed with the four-item "general fatigue" subscale of the multidimensional fatigue inventory (MFI) [47]. Scale scores ranged from 4 to 20 (M = 11.3 [SD 4.9]; α = 0.82). *Perceived physical fitness* was assessed with a ten-item subscale of the groningen fitness test for the elderly (GFE) [48], which is a comparative fitness rating using peers as a frame of reference. Scale scores ranged from 10 to 50 (M = 27.9 [SD 7.4]; α = 0.87). *Comorbidity* was assessed using an open-ended question that asked participants to list all their chronic conditions (median = 1; range 0-5).

Social status

Partner status was defined as having a partner, irrespective of cohabitation, or being single. *Social network* was assessed by four questions addressing the number of individuals within the personal network of children, relatives, friends, and neighbors. The sum score reflects the total network size (M = 20.5 [SD 13.4]). The Social Support List (subscale negative

interactions [49]) assessed *negative social support* with seven items on a 1-4 Likert scale. Scale scores ranged from 7 to 28 (M = 9.3 [SD 2.5]; α = 0.71).

Psychological status

Mental health was assessed with the five-item subscale of the RAND-36 [50,51] including items on depression and nervousness. Raw scale scores were converted to a 0-100 scale (M = 69.9 [SD 18.8]; α = 0.79). *Helplessness* was assessed with the six-item subscale of the illness cognition questionnaire (ICQ) [52]. Scale scores ranged from 6 to 24 (M = 13.6 [SD 4.8]; α = 0.84). The self-management ability scale (SMAS-30; version 1, 2004) [53] was used to measure two self-management abilities, e.g., *self-efficacy* and *taking initiatives.* Scale scores for these two five-item subscales ranged from 5 to 30 (self-efficacy M = 20.6 [SD 3.9] α = 0.74; taking initiatives M = 18.7 [SD 4.3] α = 0.68).

4.2.4 Statistical analysis

Non-response analysis was performed using the Student's *t* test and Chi-square test. Missing values were imputed according to the instructions of the questionnaires. If no instructions were available, missing values were replaced with the average score of the completed items in the scale, provided that at least 50% of the items were completed.

Multivariate hierarchical regression analyses (balanced design) were performed to examine the association between the outcome measures (i.e., participation in domestic life, interpersonal interactions and relationships, and community, social, and civic life) and the potential explanatory factors (i.e., sociodemographic, physical health, social and psychological factors, and personal values). Variables that were univariately associated with a specific participation domain (P < 0.05) were entered into the model. The entry of the variables was as follows: block 1) sociodemographic factors; block 2) physical health status; block 3) social status; block 4) psychological status; and block 5) personal values. The results were checked for multicollinearity and were below the critical multicollinearity values (correlation coefficient < 0.80 [54] and variance inflation factor < 10 [55]). Logistic regression analysis was performed for the binary outcome measure of participation in major life areas. The entry of the variables was the same as in the multivariate hierarchical regression analyses. All analyses were performed using the statistical package for the social sciences (SPSS, Inc, Chicago, IL, USA), version 16.0.

4.3 Results

Descriptive characteristics of the 173 study participants are shown in Table 4.1.

Table 4.1: Sociodemographic and vision-related characteristics, and comorbidity of the study participants (*n* = 173)

Characteristic	Value – *n* (%)[a]
Age, years	
55-74	103 (60)
≥75	70 (40)
Mean±SD	72.3 ± 9.7
Range	55-93
Gender, female	100 (58)
Partner status, partner	83 (52)
Educational level	
(Pre)primary	25 (16)
Lower secondary	47 (30)
Upper secondary	53 (34)
Tertiary	33 (21)
Income	
<€1500 a month	58 (45)
€1500-€2999 a month	57 (45)
≥€3000 a month	13 (10)
VFQ-25	
Poor, very poor, or completely blind	118 (71)
Fair, good, or excellent	48 (29)
Mean±SD	40.1 ± 18.8
Binocular visual acuity (VODS)	
Median	0.25
Mean±SD	0.75 logMAR ± 0.65 logMAR
Duration of vision loss, years	
Median	7
Primary cause of visual impairment	
Age-related maculopathy	81 (49)
Vascular disorders[b]	12 (7)
Optic nerve disorders	10 (6)
Congenital and hereditary disorders[c]	7 (4)
Corneal disorders	5 (3)
Glaucoma	4 (2)
Cataract	4 (2)
Other primary causes	12 (7)
Combination of causes	22 (13)
Cause unknown	10 (6)
Co-morbidity[d]	
None	74 (45)
1	56 (34)
≥2	35 (21)

SD Standard deviation; *VFQ* Visual Functioning Questionnaire; *VODS* Visus Oculi Dextri Sinistri
[a] Percentages are based on totals for each category, and may not total 100 because of rounding.
[b] e.g., diabetic retinopathy
[c] e.g., retinitis pigmentosa
[d] number of chronic conditions other than the eye-disease

4.3.1 Domestic life

Participation domain scores in domestic life ranged from 0 to 4 (*M* = 2.6 [SD 1.1]). Four percent of the study group did not participate in any of the four domestic life activities, whereas 23% participated in all activities. Univariate analyses showed that age, fatigue, perceived physical fitness, partner status, mental health, helplessness, self-efficacy, and taking initiatives were statistically significantly associated with participation in domestic life (Table 4.2). The other explanatory variables, including vision-related characteristics, were not associated with domestic life (range Beta: 0.01-.010; $P \geq 0.19$; data not shown). Multivariate hierarchical regression analysis (Table 4.2) showed that in the final model, Model 4, 28.3% of the total variance in participation in domestic life could be explained. Younger age, favorable perceived physical fitness, and less helplessness were associated with more participation in domestic life.

Table 4.2: Univariate and multivariate regression analyses of participation in domestic life on sociodemographic characteristics, physical health status, social status, psychological status, and personal values

	Univariate Beta	**Model 1** Beta	**Model 2** Beta	**Model 3** Beta	**Model 4** Beta
1. Sociodemographic characteristics (8.8%)[a]					
- Age	-0.30***	-0.30***	-0.33***	-0.31***	-0.22**
2. Physical health status (11.3%)[a]					
- Fatigue	-0.32***		-0.11	-0.11	-0.10
- Perceived physical fitness	0.32***		0.29**	0.29**	0.19*
3. Social status (2.5%)[a]					
- Partner status (partner)	0.16*			0.08	0.07
4 Psychological status (20.6%)[a]					
- Mental health	0.22**				-0.07
- Helplessness	-0.35***				-0.19*
- Self-efficacy	0.36***				0.07
- Taking initiatives	0.37***				0.13
5. Personal values (0.0%)[a]					
R^2-change (%)		8.8	12.8	0.5	6.2
Total R^2 (%)		8.8	21.6	22.1	28.3
F		14.7***	13.8***	10.6***	7.2***
N		154	154	154	154

Beta standardized regression coefficient
[a] Explained variance of the separate block
* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$

4.3.2 Interpersonal interactions and relationships

Fifty percent of the study group had the maximum score on participation in interpersonal interactions and relationship (*M* = 2.3 [SD 0.8]; range: 0-3). Univariate analyses with participation in interpersonal interactions and relationships as dependent variable (Table 4.3) showed statistically significant associations for fatigue, perceived physical fitness, social network size, self-efficacy, taking initiatives, and perceived importance. No significant associations were found for the other explanatory variables (range Beta: 0.01-0.15; $P \geq 0.06$; data not shown). The results of the multivariate regression analysis (Table 4.3) indicated that variables representing physical health status and psychological status were not statistically significantly related to participation in interpersonal interactions and relationships; only perceived importance was a significant determinant (Model 4; explained variance 14.5%). A higher perceived importance of relationships with family and friends was associated with a higher frequency of interactions in this domain.

Table 4.3: Univariate and multivariate regression analyses of participation in interpersonal interactions and relationships on sociodemographic characteristics, physical health status, social status, psychological status, and personal values

	Univariate Beta	**Model 1** Beta	**Model 2** Beta	**Model 3** Beta	**Model 4** Beta
1. Sociodemographic characteristics (0.0%)[a]					
2. Physical health status (2.6%)[a]					
- Fatigue	-0.17*	-0.10	-0.09	-0.08	-0.08
- Perceived physical fitness	0.18*	0.08	0.06	0.03	0.06
3. Social status (6.8%)[a]					
- Social network size	0.26**		0.25**	0.21*	0.14
4. Psychological status (4.7%)[a]					
- Self-efficacy	0.23**			0.09	0.05
- Taking initiatives	0.22**			0.01	0.00
5. Personal values (9.8%)[a]					
- Perceived importance	0.26***				0.25**
R^2-change (%)		2.6	5.9	0.6	5.4
Total R^2 (%)		2.6	8.5	9.1	14.5
F		1.9	4.4**	2.8*	4.0**
N		148	148	148	148

Beta standardized regression coefficient
[a] Explained variance of the separate block
* $P < 0.05$; ** $P < 0.01$

4.3.3 Major life areas

Twenty-seven percent of the study participants were involved in major life areas. The results of the univariate logistic regression analyses with voluntary work as the dependent variable (Table 4.4) showed an association for age, fatigue, partner status, social network size, mental health, helplessness, taking initiatives, and perceived importance. The other explanatory variables were not significantly associated with voluntary work (range OR: 0.54-1.15; $P \geq 0.08$; data not shown). Multivariate logistic regression analysis showed that in the final model, perceived importance was a significant determinant of participation in major life areas, in addition to social network size.

4.3.4 Community, social and civic life

Participation scores on the community, social, and civic life domain ranged from 0 to 7 (M = 3.0 [SD 1.6]). The results of the univariate regression analyses (Table 4.5) showed that age, income, fatigue, perceived physical fitness, partner status, social network size, helplessness, self-efficacy, taking initiatives, and perceived importance were statistically significantly associated with participation in this domain. No significant associations were found for the other explanatory variables (range Beta: 0.02-0.15; $P \geq 0.06$; data not shown). The results of the multivariate regression analysis showed that only perceived importance was associated with more participation in this domain (Model 5; explained variance 28.2%).

Table 4.4: Univariate and multivariate logistic regression analyses of participation in major life areas on sociodemographic characteristics, physical health status, social status, psychological status, and personal values

	Univariate OR (95% CI)	**Model 1** OR (95% CI)	**Model 2** OR (95% CI)	**Model 3** OR (95% CI)	**Model 4** OR (95% CI)	**Model 5** OR (95% CI)
1. Sociodemographic variables						
- Age	0.96 (0.92-0.99)*	0.97 (0.93-1.00)	0.97 (0.93-1.01)	0.98 (0.94-1.02)	0.99 (0.94-1.03)	0.99 (0.94-1.04)
2. Physical health status						
- Fatigue	0.91 (0.84-0.97)**		0.92 (0.85-0.99)*	0.92 (0.85-1.00)*	0.94 (0.85-1.03)	0.92 (0.83-1.02)
3. Social status						
- Partner status (partner)	2.08 (1.02-4.24)*			1.52 (0.68-3.43)	1.63 (0.71-3.74)	1.64 (0.63-4.24)
- Social network size	1.03 (1.00-1.05)*			1.03 (1.00-1.06)	1.02 (0.99-1.05)	1.04 (1.00-1.07)*
4. Psychological status						
- Mental health	1.02 (1.00-1.04)*				1.00 (0.97-1.02)	1.01 (0.98-1.04)
- Helplessness	0.90 (0.83-0.97)**				0.92 (0.84-1.01)	0.96 (0.87-1.07)
- Taking initiatives	1.10 (1.01-1.20)*				1.02 (0.92-1.13)	0.95 (0.83-1.07)
5. Personal values						
- Perceived importance	3.35 (2.15-5.22)***					3.78 (2.19-6.50)**
-2 log likelihood		180.5	175.6	169.6	139.5	137.9
N		151	151	151	151	151

CI 95% confidence interval; *OR* odds ratio
* $P < 0.05$; ** $P < 0.001$

Table 4.5: Univariate and multivariate regression analyses of participation in community, social and civic life on sociodemographic characteristics, physical health status, social status, psychological status, and personal values

	Univariate Beta	**Model 1** Beta	**Model 2** Beta	**Model 3** Beta	**Model 4** Beta	**Model 5** Beta
1. Sociodemographic variables (7.9%)[a]						
- Age	-0.15*	-0.13	-0.15	-0.09	-0.04	-0.07
- Income	0.26**	0.24**	0.22*	0.11	0.10	0.10
2. Physical health status (8.8%)[a]						
- Fatigue	-0.22**		-0.15	-0.12	-0.09	-0.07
- Perceived physical fitness	0.23**		0.18	0.21*	0.15	0.20
3. Social status (9.2%)[a]						
- Partner status (partner)	0.22**			0.20	0.22*	0.19
- Social network size	0.22**			0.06	0.02	-0.00
4. Psychological status (11.9%)[a]						
- Helplessness	-0.30***				-0.17	-0.12
- Self-efficacy	0.32***				0.06	0.04
- Taking initiatives	0.29***				0.02	0.05
5. Personal values (8.2%)[a]						
- Perceived importance	0.32***					0.24**
R^2-change (%)		7.9	8.2	3.4	3.4	5.3
Total R^2 (%)		7.9	16.1	19.5	22.9	28.2
F		5.0**	5.5***	4.6***	3.6**	4.3***
N		120	120	120	120	120

Beta standardized regression coefficient
[a] Explained variance of the separate block
* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$

4.4 Discussion

The purpose of this study was to assess the determinants of self-reported performance of participation in domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life among visually impaired older adults. These determinants were investigated according to the biopsychosocial model.

With respect to vision-related variables, we found that the severity, duration, and primary cause of VI had no effect on participation. This is in accordance with the study of Desrosiers et al. [37] who found that visual acuity was not associated with participation. Other measures of visual functioning (e.g., visual field, contrast sensitivity, acuteness of the onset of vision loss) may have had an impact on participation. However, these measures were not included in our study, because of the unavailability of these data for all study participants. It is beyond question that visually impaired older adults do perceive restrictions in participation [4,11,12]. Our results indicate that, although a visual impairment leads to participation restrictions, the severity of the impairment in itself has no impact on participation of visually impaired older adults.

The finding that perceived physical fitness is a determinant of participation in domestic life is not surprising, given that doing household tasks requires exertion of the physiological system (muscle mass and strength, flexibility, balance and coordination, and cardiovascular function). The association between physical fitness and participation was also found in the study of Anaby et al. [31] among older adults in general, which showed that balance and mobility affected participation in daily activities and social roles. Lamoureux et al. [11] found that physical functioning was one of the main predictors of participation restrictions among people with impaired vision. Our finding indicates that physical fitness may be an important prerequisite for participation. This knowledge can be used for the development of rehabilitative interventions.

With respect to the social status variables, only social network size was associated with participation in major life areas (i.e., voluntary work). To our knowledge, this relationship has not been studied before. Unexpectedly, social support appeared not to be related to participation. This is in contrast with the positive effect of support of family and friends on participation, as found in older adults in general [32]. We used negative interactions as an indicator of social support instead of positive aspects, such as stimulation or encouragement, which may explain the difference in findings regarding social support. Our choice to use negative social interactions as an indicator of social support was based on previous research in visually impaired older adults [56]. The low prevalence of negative social interactions in our study population, however, may also explain the lack of association between social support and participation.

The psychological status variables (i.e., mental health, helplessness, self-efficacy, and taking initiatives) contributed to the explained variance of participation across the domains. However, a significant association was only found for the domestic life domain; a higher level of helplessness was associated with decreased participation in domestic life. Helplessness refers to an attributional style, explaining negative events and their consequences as uncontrollable, unpredictable, and unchangeable [52]. Negative outcome expectancies and negative attributions with regard to vision loss may lead to avoidance behavior. To our knowledge, only Lindo and Nordholm [57] assessed the relationship between helplessness and participation. In a sample of visually impaired adults of working age, they found that helplessness was associated with perceived difficulties in cleaning the home, shopping, leisure activities, and socializing. Despite the modest associations we found in the multivariate models, it seems important to assess psychological functioning in relation to participation [37].

Perceived importance of participation appeared to be a major determinant in three out of the four participation domains (i.e., interpersonal interactions and relationships, major life areas, and community, social and civic life). Importance refers to the value that an individual attaches to a specific domain and may influence the motivation and choice to engage in a specific domain of participation. In the domestic life domain, however, we found no association for perceived importance. This may be explained by the fact that household activities and shopping are necessities of daily life, irrespective of how one values these activities.

One of the limitations of the present study is the cross-sectional design which limits the inferences of causality. The inclusion of study participants from a low-vision rehabilitation center may imply the selection of relatively motivated visually impaired older adults. Furthermore, the self-report data derived through telephone interviews may imply social desirability bias. With respect to the outcome measure of the study, there is no consensus yet on how participation should be measured [58]. At the time of data collection, we concluded, based on a review of Perenboom and Chorus [59] and on our own literature review, that there was no participation questionnaire available that suited the aim of our study, namely to measure self-reported performance of participation. Therefore, we assessed participation by means of items extracted from available population surveys [41-43], and computed participation domain scores by a summation of the frequency of activities. The actual scores, however, are less than the theoretical maximum because of the limits to a person's time, resources and energy [60]. We followed one of the options given by the ICF for differentiating "Participation" from "Activities", and identified four chapters that represent participation. Whether the "Domestic life" chapter is a domain of participation, or whether it is merely connected to activities, is debatable. Whiteneck and Dijkers [61] recently stated that this chapter is the most difficult to allocate to activity versus

participation, and concluded that domestic life focused mainly on individual activities. If so, this may be another explanation that perceived importance was not related to participation in domestic life activities.

Despite the comprehensive biopsychosocial model, the variance in participation could only partially be explained (range 14.5-28.3%). The low explained variance of participation in interpersonal interactions and relationships may be caused by the positively skewed distribution and consequently small variance of this outcome measure. Another reason may be that participation has multiple determinants which makes it difficult to explain participation more accurately [62]. Factors that were not included in our study may have been a barrier for participation of our study participants, such as the availability of (public) transport and accessibility of (public) buildings.

To our knowledge, this is the first study that applied a biopsychosocial model in order to investigate determinants of self-reported performance of participation in visually impaired older adults. Knowledge of the factors that influence participation is relevant, since participation contributes to quality of life and well-being [18-20]. The results of the present study may guide the development of future low-vision rehabilitation interventions. The relevance of personal values attached to participation in specific domains underlines the need to assess these values before starting rehabilitation in order to facilitate individual goal-setting. Furthermore, interventions should have a multidisciplinary approach, including physical, psychological and social work intervention techniques. Group rehabilitation, instead of an individual approach, is advised because it facilitates sharing experiences and coping strategies between the visually impaired, and may extend the social network. Future studies are needed to study the effectiveness of multidisciplinary group rehabilitation interventions on participation in society.

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5

Loneliness and self-management abilities in the visually impaired elderly

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ABSTRACT

Objectives: To describe the degree of loneliness among the visually impaired elderly and to make a comparison with a matched reference group of the normally sighted elderly. In addition, we examined self-management abilities (SMAs) as determinants of loneliness among the visually impaired elderly.

Methods: In a cross-sectional study, 173 visually impaired elderly persons completed telephone interviews. Loneliness and SMAs were assessed with the Loneliness Scale of De Jong Gierveld and the SMAS-30, respectively.

Results: The prevalence of loneliness among the visually impaired elderly was higher compared to the reference group (50% vs. 29%; p <.001). Multivariate hierarchical regression analysis showed that the SMA self-efficacy, partner status, and self-esteem were determinants of loneliness. Severity and duration of visual impairment had no effect on loneliness.

Discussion: The relationship between SMAs (i.e., self-efficacy) and loneliness is promising, as SMAs can be learned through training. Consequently, self-management training may reduce feelings of loneliness.

5.1 Introduction

The prevalence of visual impairment increases exponentially above the age of 50 [1]. A recent study in the Netherlands has reported a prevalence rate of 10.2% for visual impairment (visual acuity <0.3 Snellen) in the elderly aged 65 and above [2]. The majority (79%) of the total number of visually impaired persons are 65 years and above [2]. Due to the aging of the population and a longer life expectancy, the prevalence of impaired vision is expected to increase in the future [1,3].

Previous research reported that visual impairment had a profound impact on the daily life and functioning of visually impaired people [4-6] as indicated by impaired functional ability, psychosocial problems [7-9], participation restrictions in daily life such as mobility outside the home [10], social isolation [11] and feelings of loneliness [12].

Loneliness is an unpleasant experience, encompassing a lack of (quality of) certain relationships, which results in a decrease of well-being [13]. It is well known that poor vision is associated with loneliness [12,14-16]. Prevalence rates of loneliness in visually impaired persons, however, vary. A study among blind American veterans (mean age 62 years) found that 20% reported feelings of loneliness according to the UCLA Loneliness Scale [15]. In contrast, a Dutch study among new elderly clients (aged ≥55 years) of a low-vision rehabilitation center found that 54% reported loneliness according to the Loneliness Scale of De Jong Gierveld [12].

Knowledge about the determinants of loneliness is needed to prevent or reduce feelings of loneliness. Determinants of loneliness in the general population of the elderly include general health problems [17-20], widowhood [17,21], living alone [17,21], a small social network [18,22], a lack of social support [13] and reduced self-esteem [23]. Studies among the visually impaired elderly have shown that duration of visual impairment [15], adaptation to vision loss [12], a lack of social support [12], a small supporting social network [14], activity loss [15], and personality characteristics [16] are determinants of feelings of loneliness.

Self-management, which becomes more important as age increases, is considered as an important social skill and is expected to play an important role in explaining differences in feelings of loneliness in visually impaired elderly persons. To our knowledge, no studies among visually impaired people are available with respect to the relationship between self-management abilities and loneliness. Relevant in this respect may be the self-management well-being theory (SMWT) of Steverink, Lindenberg and Slaets [24]. Although this theory is intended to explain differences in well-being, it may also apply to other outcome measures, such as feelings of loneliness. Moreover, loneliness is often considered to be an indicator of lack of well-being [13,25,26].

According to this SMWT [24], two kinds of resources can be distinguished. The first one encompasses external resources which contribute to well-being from the “outside” such

as friends and social support. The second one encompasses internal resources which refer to behavioral and cognitive abilities that people use to manage their external resources and thus achieve well-being. Having external resources is essential but not sufficient for the maintenance of well-being. People also need to be able to manage these external resources [24]. For example, having social relationships requires the management ability to indeed achieve and maintain social support from these relationships. Steverink et al. [24] introduced the term *self-management abilities* (SMAs) to represent these internal resources, which were identified as self-efficacy, positive frame of mind, taking initiatives, investment behavior, multifunctionality of resources, and variety in resources.

SMAs may be particularly important for the visually impaired elderly. Along with the general consequences of aging, these elderly will experience additional restrictions due to vision loss and, as such, will be doubly burdened [27]. Due to vision loss, the management of external resources (e.g., friends, social support) may become more difficult. As a result, they may experience feelings of loneliness. The application of SMAs may be able to support the visually impaired elderly in managing a decline in these external resources, which accordingly will enable them to experience well-being and fewer feelings of loneliness. Interindividual differences in the way visually impaired older adults proactively cope with feelings of loneliness may be attributed to discrepancies in the degree and extent to which they are able to apply SMAs.

In this study, we will focus on two specific SMAs: self-efficacy and taking initiatives. Self-efficacy is a cognitive SMA and refers to the ability to gain and to maintain a belief in personal competence or control in achieving various aspects of well-being [24]. The higher a person's self-efficacy belief with respect to obtaining external resources, the more likely it will be that the person will undertake those activities and apply the effort needed to do so. However, a high self-efficacy belief is not sufficient. Even if people feel efficacious, they do need to take specific actions in order to achieve desired results. Therefore, an active-motivational SMA such as taking initiatives is essential [24]. The SMA taking initiatives refers to the ability to be self-motivating or proactive as opposed to being or feeling passive, dependent or fatalistic. It is hypothesized that taking initiatives with regard to important resources is necessary for the achievement and maintenance of well-being [24,28]. The two SMAs self-efficacy and taking initiatives have been chosen because of their considerable contribution to the overall concept of self-management [28]. Moreover, these abilities are expected to be important for coping with feelings of loneliness.

The first aim of this study is to identify the degree to which visually impaired elderly persons experience feelings of loneliness as compared to their non-visually impaired peers. A second aim is to examine the SMAs self-efficacy and taking initiatives as determinants of loneliness among visually impaired older adults.

5.2 Methods

5.2.1 Study population

An age stratified sample (*N*=350) was drawn from 786 newly registered clients of Royal Dutch Visio, a low-vision rehabilitation center, between July 1, 2006 and June 30, 2007. Inclusion criteria were: (a) aged ≥55 years; (b) able to speak Dutch; (c) able to understand instructions concerning response sets; and (d) referred to a low-vision rehabilitation center according to the "Guidelines on the referral of visually impaired persons to low-vision services" [29]. According to these evidence-based guidelines of the Dutch Society of Ophthalmology, persons with a visual acuity <0.3 Snellen and/or visual field <30 degrees in the better eye should be referred for rehabilitation to a low-vision rehabilitation center. In addition, persons with a visual acuity ≤0.5 Snellen who experience problems with reading or other daily life activities due to visual impairment and who have a well-defined request for help should be referred to a low-vision rehabilitation center as well. Participants were excluded when they had a mental disorder (e.g., dementia), a hearing impairment, or if they were hospitalized. From this sample, a total of 264 persons were eligible for participation in the study and 173 persons agreed to participate (response 66%). Nonresponse analyses showed that study participants (*M*age=72.3 years; *SD* = 9.7) were younger than nonresponders (*M*age=78.5 years; *SD* = 9.7; $t(262) = -5.0$, $p < .001$). No difference was found with respect to gender ($p = .45$). For the nonresponders for whom the reasons for refusal were known ($n = 62$), the major reasons for refusal were: the interview takes too long or is expected to be too tiresome (32%), a lack of interest (31%), health problems (18%), a lack of time (10%), and other reasons (10%). For the remaining nonresponders ($n = 29$), the reasons for refusal were unknown.

5.2.2 Design and procedure

Data for this cross-sectional study were collected by means of telephone interviews performed by experienced interviewers who received an additional training session. Prior to the interview participants gave their informed consent. The study design was reviewed by the Medical Ethics Review Committee of the University Medical Center Groningen.

5.2.3 Reference population

The Longitudinal Aging Study Amsterdam (LASA) [30] was used as a reference population to address the first aim of this study, that is, to compare the prevalence of loneliness among visually impaired versus normally sighted elderly persons. LASA is a longitudinal multidisciplinary study which focuses on predictors and consequences of aging. In 1992, a first cohort included 3,107 persons aged 55 to 85 years. The sample was based in three culturally distinct geographical areas in the west, northeast, and south of the Netherlands

and included middle- to large-size cities as well as rural municipalities. A second cohort of 1,002 participants (aged 55 to 64 years) started in 2002 to be able to distinguish between age, cohort, and period effect. Every 3 years, the participants are reexamined. Data from the follow-up measurement in 2005-2006 of both cohorts were used for the present study (*N* = 1,805; age range: 57-97 years). LASA participants who reported difficulties with seeing (*n* = 225), hearing (*n* = 413), or with both (*n* = 180) were excluded for analysis. To preclude confounding, the reference group was frequency-matched on age, gender, and partner status (*n* = 258).

5.2.4 Measures

Loneliness

Loneliness is a situation experienced by an individual, where there is an unpleasant or inadmissible lack of (quality of) certain relationships [13]. Loneliness was assessed by the 11-item Loneliness Scale [31,32]. Examples of items are: "There is always someone I can talk to about my day to day problems" and "I miss having a really close friend". Response categories are "yes", "more or less", and "no". Item scores were dichotomized in agreement with the scaling procedure; the response "more or less" indicates loneliness. The Loneliness Scale score was computed as the sum of the dichotomized items, ranging from 0 (*absence of loneliness*) to 11 (*extreme loneliness*). A Loneliness Scale score of 3 or higher is considered as the presence of loneliness [33]. The Cronbach's alpha (α) for the scale was .86.

Sociodemographic variables

The following sociodemographic characteristics were assessed: age, gender, and educational level as an indicator of socio-economic status (International Standard Classification of Education (ISCED)) [34].

Physical status

A) Vision-related variables. Self-perceived vision was measured with the single-item subscale General Vision from the Visual Functioning Questionnaire (VFQ-25) [35]. The question was: "At the present time, would you say your eyesight using both eyes (with glasses or contact lenses) is excellent, good, fair, poor, very poor, or are you completely blind?" According to the manual, the subscale was coded and transformed to a score ranging from 0 to 100, with a higher score indicating better vision (*M* = 40.1 [*SD* = 18.8]). Duration of vision loss was computed by subtracting self-reported age at onset of vision loss from a participant's age. Data with respect to the degree of visual impairment, as indicated by corrected binocular visual acuity at distance (VODS), were collected from medical files available at the low-vision rehabilitation centers of Visio such as the referral form of the treating ophthalmologist of

the hospital. If this form was unavailable, the report of the optometrist at Visio was used. Visual acuity values were transformed to logMAR values (-log visual acuity).

B) Health-related variables. The General Health Perceptions subscale of the RAND-36 [36,37] was used to assess the subjective evaluation of the participant's general health. This subscale consists of five items. Sample items are: "In general, would you say your health is excellent, very good, good, fair, or poor?" and "I am as healthy as anybody I know". The raw scale score was converted to a 0-100 scale, with a higher score indicating a better subjective evaluation of the participant's health. A lower score indicates an evaluation of the participant's general health as poor and likely to become worse (M = 54.2 [SD = 22.7]; α = .77). To assess comorbidity, participants were asked by means of an open-ended question to list all chronic conditions they were suffering from other than their eye disease. The number of conditions reported was used as a comorbidity variable (median=1).

Social status

To identify the extent of the ego-centered social network, study participants were requested to indicate the number of individuals within the four different networks of children, relatives, friends, and neighbors. An example of the items is: "With how many of your children do you have regularly contact, that is face-to-face contact, contact by telephone, mail or e-mail?" The size of the social network was established by summing the extent of the four networks (M = 20.5 [SD = 13.4]). Partner status was a nominal variable with two categories: having a partner whether they were living together and not having a partner.

Psychological status

Self-esteem, defined as a person's overall evaluation or appraisal of his or her own worth, was measured by the Rosenberg Self-Esteem Scale (RSE) [38], which consists of 10 items, 5 positively stated and 5 negatively stated. Examples of items are "I feel that I have a number of good qualities" and "All in all, I am inclined to feel that I am a failure". Response categories range from 1 (*strongly agree*) to 4 (*strongly disagree*). The total scale scores ranged from 10 to 40 with higher scores indicating more self-esteem (M = 30.6 [SD = 4.7]; α = .85).

Self-management abilities

The Self-Management Ability Scale (SMAS-30 [version 1, 2004]) [28] was used to measure the SMAs self-efficacy and taking initiatives. Sample items from the self-efficacy subscale are: "Are you able to find agreeable activities?" and "Are you able to have friendly contacts with others?". Sample items from the taking initiatives subscale are: "How often do you take the initiative to get in touch with people who are dear to you?" and "How often do you take the initiative to keep yourself busy?". Both subscales consist of five items and response categories range from 1 (*never*) to 6 (*very often*). Scale scores range from 5 to 30, with

higher scores indicating having more SMAs (self-efficacy: *M* = 20.6 [*SD* = 3.9]; α = .74; taking initiatives: *M* = 18.7 [*SD* = 4.3]; α = .68).

5.2.5 Statistical analysis

Student's *t* tests and chi-square tests were performed for nonresponse analyses within the study group of visually impaired elderly persons. As to the first aim of this study, the prevalence and level of loneliness of the visually impaired were compared with the LASA reference group by using the chi-square test and Student's *t* test. The significance level was set at .05 (one-sided).

As to the second aim of this study, in the visually impaired study group, a hierarchical regression analysis (balanced design) with loneliness as a dependent variable was conducted. The independent variables were chosen based on relationships described in the literature. To get insight in the association between loneliness and the independent variables at the bivariate level, we computed Pearson's correlation coefficients. For the multivariate hierarchical regression analysis all variables were entered into the model. In determining the sequence of the variables to be entered in this analysis, we followed a biopsychosocial model. Since sociodemographic variables were expected to influence the other independent variables, they were entered in the first step (Block 1). Physical status variables were entered in Block 2 because of the expected effect on social status variables. The social status variables were entered in Block 3 assuming those influenced the psychological status variables that were entered in Block 4. In Block 5, the SMAs self-efficacy and taking initiatives were entered into the model. This final step gives insight in the effect of SMAs on loneliness after controlling for other variables in the biopsychosocial model. The results were checked for multicollinearity which showed that all values were below the critical multicollinearity values (correlation coefficient <.80 [39]; and variance inflation factor <10 [40]).

All analyses were performed using the statistical software package SPSS, version 16.0 (SPSS, Inc., Chicago, IL).

5.3 Results

Table 5.1 shows the demographic and clinical characteristics of the study participants.

Table 5.1: Demographic and clinical characteristics of the visually impaired study participants

Characteristic	Value – *n* (%)
Age, year (*n* = 173)	
55-74	103 (60)
≥75	70 (40)
M ± SD	72.3 ± 9.7
Gender, female (*n* = 173)	100 (58)
Partner status, partner (*n* = 161)	83 (52)
Educational level (*n* = 158)	
(Pre)primary	25 (16)
Lower secondary	47 (30)
Upper secondary	53 (34)
Tertiary	33 (21)
Self-perceived vision (VFQ-25) (*n* = 166)	
M ± SD	40.1 ± 18.8
Excellent or good	8 (5)
Fair	40 (24)
Poor	68 (41)
Very poor	44 (27)
Completely blind	6 (4)
Duration of vision loss (years; *n* = 165)	
Median	7
Binocular visual acuity (VODS; *n* = 163)	
Median	0.25
M ± SD	0.75 logMAR ± 0.65 logMAR
Co-morbidity (*n* = 166)	
0	75 (45)
1	56 (34)
≥2	35 (21)
Type of co-morbid diseases (*n* = 165)	
Diseases of the circulatory system	29 (18)
Diseases of the respiratory system	11 (7)
Diseases of the nervous system	9 (5)
Diseases of the vestibular system	8 (5)
Diabetes mellitus	19 (12)
Osteoarthritis	11 (7)
Rheumatoid arthritis	8 (5)
Other chronic conditions	45 (27)

Note: Percentages are based on totals for each category and may not total 100 because of rounding.

The participants' ages ranged from 55 to 93 years (*M* = 72 years). About 52% of the participants had a partner. With respect to vision-related characteristics, the median duration of vision loss was 7 years. The binocular visual acuity ranged from 0.001 to 1.25 (20/20000 – 20/16; median = 0.25). Five percent of the participants were blind (VODS < 0.05). The mean score on the general vision subscale of the VFQ-25 was 40, which corresponds to poor vision. More than half of the participants (55%) had one or more chronic conditions other than their eye disease (range 0-5, median = 1). The mean score on the SMAS-30 self-efficacy subscale was 20.6 (*SD* = 3.9) and the mean score on the taking initiatives subscale was 18.7 (*SD* = 4.3).

Frequency-matching of the LASA population resulted in a reference group of 258 normally sighted elderly persons. The mean age of the reference group was 72 years (*SD* = 9.2). Fifty-seven percent of the reference group were female, and 52% had a partner. There were no differences with respect to age (*p* = .75), gender (*p* = .87), and partner status (*p* = .94) between the LASA reference group and the visually impaired study participants.

Loneliness was present in 50% of the visually impaired study participants. Of those who experienced loneliness (*n* = 79), 14% were extremely lonely (scores 9 through 11) and 86% moderately lonely (scores 3 through 8). Of the normally sighted reference group, 29% experienced loneliness, which is a significantly lower percentage ($p < .001$). The average loneliness score in the study group was 3.3 (*SD* = 3.1) and in the LASA reference group 2.0 (*SD* = 2.6). Visually impaired study participants experienced more feelings of loneliness than the normally sighted reference group (mean difference = 1.3; 95% CI [0.7, 1.9]).

Table 5.2 summarizes the correlation matrix for all sociodemographic, physical (i.e., vision-related and health-related), social, and psychological statuses, along with self-management variables with the dependent variable loneliness as measured in the visually impaired study group.

Table 5.2: Correlation between independent variables and the dependent variable loneliness in the visually impaired study group

Independent variables	Sample size (*N*)	Loneliness (*r)*
1. Sociodemographic variables		
- Age	161	.13
- Gender[a]	161	.04
- Educational level	155	-.10
2. Physical status:		
2a. Vision related variables		
- Self-perceived general vision	161	-.10
- Duration of vision loss	160	.08
- Degree of visual impairment	151	-.06
2b. Health-related variables		
- General health perceptions	161	-.23**
- Comorbidity	154	.14
3. Social status		
- Social network size	153	-.06
- Partner status[b]	160	-.36***
4. Psychological status		
- Self-esteem	155	-.39***
5. Self-management abilities		
- Self-efficacy	158	-.51***
- Taking initiatives	156	-.38***

Note: r = Pearson correlation coefficient
[a] 0 = *male*, 1 = *female*;
[b] 0 = *no partner*, 1 = *having a partner;*
* *p* <.05; ** *p* <.01; *** *p* <.001.

Of special interest were the correlations between loneliness and the SMAs self-efficacy and taking initiatives which were statistically significant (*r* = -.51 and *r* = -.38, respectively). These results indicate that at the bivariate level less self-management behavior was associated with more severe feelings of loneliness. Other independent variables that correlated significantly with loneliness were general health perceptions (*r* = -.23), having a partner (*r* = -.36) and self-esteem (*r* = -.39). The correlation between the two SMAs self-efficacy and taking initiatives was .67 (*p* < .001). All other mutual correlations between the independent variables were ≤.52.

Table 5.3 shows the results of the multivariate hierarchical regression analysis with loneliness as the dependent variable. From the analysis, it appears that each block with independent variables entailed a substantive contribution to loneliness in visually impaired study participants. The sociodemographic variables accounted for 5.2% of the explained variance (Model 1). Physical status variables accounted for an additional 6.1% of the explained variance (Model 2) and social status variables for 9.8%, respectively (Model 3).

Model 4 showed that psychological status variables added 10.2% to the explained variance in loneliness. In the final step (Model 5), the SMAs accounted for an additional 9.8% explained variance. The total variance in loneliness that could be explained by the model was 41.1%.

The standardized regression coefficients of the final model represent the relative contribution of the variables to the explanation of loneliness. Model 5 shows that the SMA self-efficacy had the highest standardized regression coefficient: participants with more self-efficacy experienced fewer feelings of loneliness. Other significant determinants of loneliness were partner status and self-esteem indicating that having a partner and having more self-esteem were directly associated with fewer feelings of loneliness. The SMA taking initiatives was not a significant determinant of loneliness.

Table 5.3: Multivariate hierarchical regression analysis of loneliness in the visually impaired study group

Block	Model 1 β	Model 2 β	Model 3 β	Model 4 β	Model 5 β
1. Sociodemographic variables					
- Age	.18*	.21*	.10	.07	.01
- Gender (female)	.02	.05	-.06	-.08	-.04
- Educational level	-.12	-.11	-.10	-.08	.02
2. Physical status:					
2a. Vision-related variables					
- Self-perceived general vision		.02	.00	-.02	-.06
- Duration of vision loss		.13	.08	.08	.13
- Degree of visual impairment		-.04	.00	-.02	-.06
2b. Health-related variables					
- General health perceptions		-.16	-.20*	-.04	.02
- Comorbidity		.13	.14	.09	.12
3. Social status					
- Social network size			-.03	-.07	-.02
- Partner status (partner)			-.35***	-.32**	-.30***
4. Psychological status					
- Self-esteem				-.37***	-.19*
5. Self-management abilities					
- Self-efficacy					-.41**
- Taking initiatives					.01
R^2-change (%)	5.2	6.1	9.8	10.2	9.8
Total R^2 (%)	5.2	11.3	21.1	31.3	41.1
F	2.27	1.87	3.10**	4.76***	6.06***
N	127	127	127	127	127

Note: β = standardized regression coefficient
* p <.05; ** p <.01; *** p <.001

5.4 Discussion

In this study, we identified the prevalence and degree of loneliness among visually impaired elderly persons and made a comparison with a matched reference group of normally sighted elderly persons. In addition, we examined determinants of loneliness among the visually impaired study participants with a special focus on the SMAs self-efficacy and taking initiatives. These abilities may support the visually impaired elderly in coping with feelings of loneliness. Our study showed that the visually impaired elderly are at risk for loneliness; they experience significantly more loneliness than normally sighted elderly persons. Furthermore, the results showed that the SMA self-efficacy, partner status, and self-esteem were directly associated with loneliness among visually impaired elderly persons. Severity and duration of visual impairment had no effect on loneliness.

We found a high prevalence of loneliness among the visually impaired elderly persons, namely 50% which is in line with another Dutch study [12] that reports a prevalence of 54% in the visually impaired elderly aged ≥55 years using the same Loneliness scale of De Jong Gierveld. These prevalence rates are higher than the prevalence of 20% found among blind American veterans [15]. Evans [15], however, used the UCLA Loneliness scale to assess loneliness which may account for the difference. In our reference population of normally sighted elderly, 29% reported loneliness. Among the general Dutch population, Van Tilburg [41] found a prevalence of 30%. The significantly lower rate of loneliness in the matched reference group of the LASA study therefore justifies the conclusion that the visually impaired elderly experience more feelings of loneliness than the normally sighted elderly.

The pattern of relationships observed between loneliness and the independent variables suggests that visually impaired elderly persons who have more self-efficacy experience fewer feelings of loneliness. In addition, visually impaired elderly persons who have higher self-esteem and who have a partner report fewer feelings of loneliness, which is consistent with the literature not only in studies on visually impaired people [12] but also in the general population [17,21].

In this study, we were particularly interested in the effect of the SMAs self-efficacy and taking initiatives on loneliness. SMAs are means by which people are able to manage their external resources, such as friends and social support, which are important contributors to well-being [24]. Having more SMAs enables people to access these external resources. The exchange of social support within the social network is an important indicator of how well the network functions. More supportive relationships indicate less loneliness [42,43]. Therefore, SMAs can be regarded as skills which are necessary to obtain social relationships and social support which may protect elderly persons against feelings of loneliness.

Our results showed that the SMA self-efficacy was the strongest determinant of loneliness. If visually impaired elderly persons have more self-efficacy, they appear to have

fewer feelings of loneliness. This result is in accordance with studies among the normally sighted elderly by Fry and Debats [44] and by Cohen-Mansfield and Parpura-Gill [45]. In contrast, the SMA taking initiatives was not a significant determinant in the multivariate model, although analysis at the bivariate level indicated an association with loneliness. Although both SMAs are closely related, they are considered as separate abilities. The belief in one's competence is not automatically linked to the motivation to use one's competence. Our results indicate that the belief in one's competence or control is more important in proactively coping with feelings of loneliness than is the motivation to use this competence. However, our results do not mean that taking initiatives is an insignificant ability. According to the SMWT of Steverink et al. [24], SMAs reinforce each other and cumulate to higher levels of self-management.

Interestingly, we found no significant association between loneliness and the vision-related characteristics included in this study (e.g., self-perceived vision, duration of vision loss, and degree of visual impairment). Apparently, merely having a visual impairment is associated with more feelings of loneliness, whereas the severity and the duration of the visual impairment play no additional or significant role within a sample of highly visually impaired persons. Another surprising finding was the lack of a significant association between loneliness and the social network. This is in contrast with previous studies in older adults, which showed that the size and the heterogeneity of the network influenced the exchange of social support and feelings of loneliness [18,22,46-48]. The subjective evaluation of the social network, however, is a mediating factor between the descriptive, objective characteristics of the network and loneliness [13]. Our study only assessed objective characteristics of the social network which may explain the absence of an association with loneliness. Another explanation may be that the effect of social network on loneliness in the visually impaired elderly primarily is mediated by the partner, considering our finding that partner status was an independent determinant of loneliness.

To our knowledge, this is the first study that compares the prevalence and degree of loneliness among the visually impaired elderly with a matched reference group of the normally sighted elderly. In addition, the relationship between SMAs and loneliness in the visually impaired elderly has not been studied before, which is a strength of the present study. However, the cross-sectional design of the study limits the inferences of causality. Longitudinal research is needed to determine the causal dynamics in adaptation to vision loss, as well as to confirm the effects of SMAs. Concerning the generalizibility of our findings to the Dutch population of the visually impaired elderly, it should be noted that the present study included the visually impaired elderly who were referred to and registered at a low-vision rehabilitation center. Inclusion through a low-vision rehabilitation center may implicate selection of a subgroup of the visually impaired elderly who are motivated to seek rehabilitation. The response rate of 66% and the fact that nonresponders were older may have resulted in a response bias. Furthermore, missing data resulted in a relatively

smaller analytic sample for the regression analysis. An item nonresponse analysis, however, indicated no differences between persons who were included versus excluded in the regression model with respect to sociodemographic, vision-related, health-related, social status and psychological status variables, and self-management abilities. Moreover, clinical measures of acuity may be incomplete, as they do not include important other indicators like visual fields and contrast sensitivity. These factors were not examined due to unavailability of these data for all study participants. With respect to the selection of the reference group of the LASA population, we used data on self-perceived vision because of insufficient objective measures of the degree of visual impairment. Last, it would have been interesting to perform a hierarchical regression analysis for the reference group in order to examine differences in determinants of loneliness between the visually impaired and normally sighted elderly. As the LASA study does not include the measurement of SMAs, this will remain an area for future research.

To conclude, our study showed that visually impaired elderly persons are burdened by the unpleasant feeling of loneliness. This is a profound and worrisome issue in view of the expected increase in the number of visually impaired older adults in the future [1]. The results of this study add new insights into the factors of loneliness. This knowledge can be used in the field of low-vision rehabilitation, in particular in the development of interventions aimed to reduce loneliness. Our results suggest that self-management training may be effective in reducing feelings of loneliness among the visually impaired elderly. Self-management training provides the visually impaired elderly with skills and resources to manage the practical, social, and emotional consequences of vision loss, and as a result may reduce feelings of loneliness. Recent studies have shown that self-management training can enhance the SMAs of the visually impaired elderly [49,50]. Future studies have to show if the self-management training is effective in reducing loneliness.

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6

Effects of a multidisciplinary group rehabilitation programme on participation of the visually impaired elderly: a pilot study

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ABSTRACT

Purpose. To pilot test the newly developed multidisciplinary group rehabilitation programme *Visually Impaired elderly Persons Participating (VIPP)*.

Method. A single group pre-test post-test design pilot study included 29 visually impaired persons (≥55 years). The intervention (20 weekly meetings) consisted of four components (practical training; education, social interaction, counselling and training of problem-solving skills; individual and group goal-setting; home-based exercise programme). Participation was assessed with the Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P) and the Impact on Participation and Autonomy questionnaire (IPA) at baseline, immediately and six months after the intervention.

Results. At scale level, no statistical significant changes over time were found whereas the effect size indicated small effects for restrictions and satisfaction with participation, and a medium effect for autonomy outdoors. At item level, improvements tended to occur in frequency of housekeeping, in restrictions in housekeeping and outdoor activities, and in satisfaction with the partner relationship. Satisfaction with leisure indoors and autonomy regarding using leisure time tended to increase as well.

Conclusions. The tentative conclusion of this small-scale pilot study is that the *VIPP*-programme modestly benefits perceived restrictions in participation, satisfaction with participation and autonomy outdoors of the visually impaired elderly. These preliminary findings warrant further investigation.

6.1 Introduction

Decline in visual function is a major concern in the elderly population. Visual impairment is estimated to affect 10.2% of the Dutch people older than 65 years [1]. In the next decades, the aging of the population will lead to an increase in the number of visually impaired elderly persons [2,3]. Previous research showed that vision loss has a profound impact on daily functioning [4-6] and quality of life [7-10], as indicated by an impaired functional ability and psychological distress [11-13]. In addition, visually impaired elderly persons perceive restrictions in participation [14,15] and participate less in household activities, sports activities and recreational activities as compared to peers [14].

With the International Classification of Functioning, Disability and Health (ICF; [16]) the World Health Organization (WHO) underlines the importance of participation – defined as 'involvement in life situations' – as an outcome of health. Participation is a means of experiencing social connectedness with other people [17] and is associated with a reduced risk of cognitive [18] and functional decline [19,20]. Participation also contributes to quality of life and well-being [21-23]. Therefore, it is important that visually impaired elderly persons maintain or enhance their level of participation in society.

Low-vision rehabilitation services aim to enhance the independence of visually impaired persons. Previous studies reported the effects of low-vision rehabilitation on participation of elderly persons. An early study in the legally blind elderly showed an increase in household activities after group therapy by telephone [24]. More recently, a vision self-management programme resulted in an increase in participation in life situations [25,26]. Lamoureux et al. [27] found a decrease in participation restrictions after a multidisciplinary low-vision rehabilitation programme. A pilot study on a psychosocial intervention programme for the elderly with age-related macular degeneration indicated an improvement in perceived autonomy in participation [28]. In contrast, the study of Brody et al. [29] showed mixed results of a self-management group intervention; participation in some activities increased (e.g. gardening) whereas other activities (e.g. going to movies and cultural events) decreased. In sum, these studies indicate the benefit of low-vision rehabilitation on participation of elderly persons.

The afore cited studies applied various models of low-vision rehabilitation services with substantial differences in content, intensity and duration. In the Netherlands, current low-vision rehabilitation services focus on information, advice and the provision of low-vision aids, as well as advice on adaptation of the home and work environment [30]. In addition, occupational therapists provide training of activities of daily living and training in orientation and mobility, whereas social workers provide counselling. The majority of these services in the Netherlands are provided on an individualized basis. Previous research, however, has shown that contacts with others in a similar situation are highly valued by visually

impaired persons [31]. Group-based programmes not only provide the opportunity of social interaction but also allow participants to share a range of experiences and coping strategies for both functional and emotional issues [31].

Therefore, we developed a multidisciplinary group rehabilitation programme, *Visually Impaired elderly Persons Participating (VIPP)*, which aims to enhance the degree of participation of the visually impaired elderly. This pilot study conducts a preliminary investigation of the effectiveness of *VIPP* on four different aspects of participation: frequency, restrictions, satisfaction and autonomy.

6.2 Methods

6.2.1 Study participants

Study participants originated from a previous cross-sectional study [14] that included visually impaired persons who were aged ≥55 years, able to speak Dutch, able to understand instructions concerning response sets and referred to a low-vision rehabilitation centre according to the Dutch guidelines [32]. According to these guidelines, persons with a visual acuity <0.5 Snellen who have problems in daily life due to the visual impairment should be referred for rehabilitation as well as persons with a visual field <30 degrees. Study participants were eligible for this pilot study if they were able to walk (with or without a walking aid) and if they had a total score ≤7 on outdoor participation, measured as going out to recreational, cultural and public places (response category: 0 [never] – 5 [once a week or more]; total score range: 0-15). In November 2008, 134 visually impaired elderly persons received information about the *VIPP*-programme by mail. By returning a reply card, subjects could indicate whether they were interested to cooperate. Subjects who did not respond within three weeks received a reminder phone call. Forty-three elderly (32%) were interested and received detailed information about the *VIPP*-programme by phone. Finally, 29 (22%) persons gave informed consent of which 26 (90%) completed the whole intervention programme. Figure 6.1 shows a flow diagram of the inclusion of the study subjects.

Non-response analysis showed no significant differences between those who participated in the study and those who declined (n=87) with respect to age, gender, partner status and binocular visual acuity ($p>0.05$). In addition, there were no differences in pre-intervention levels of participation between responders and non-responders, as measured in the previous study ($p>0.05$; [33]).

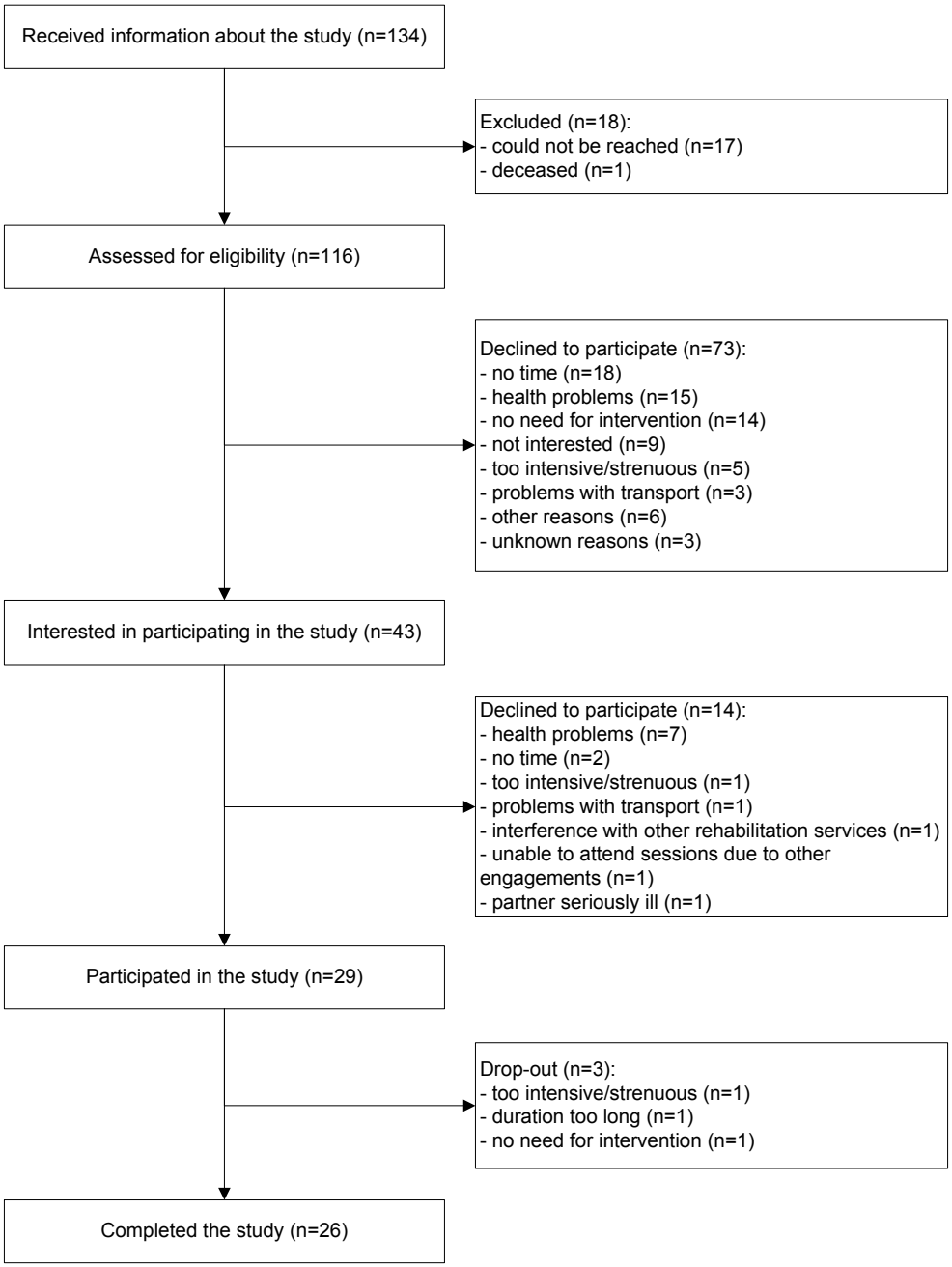

Figure 6.1: Flow diagram of inclusion of the study subjects

6.2.2 Design

This pilot study had a single group pre-test post-test design. Data were collected by means of face-to-face interviews at baseline (pre-test T0 – January 2009), immediately after the completion of the intervention (short-term post-test T1 – June 2009), and six months later (long-term follow-up T2 – December 2009). Interviews were performed by trained interviewers at the intervention location. All subjects provided written informed consent. The Medical Ethics Committee of the University Medical Center Groningen reviewed the study protocol. The study followed the tenets of the Declaration of Helsinki.

6.2.3 Development of the VIPP-programme

The multidisciplinary group rehabilitation programme *VIPP* was developed according to the principles of intervention mapping [34,35], a stepwise procedure for developing theory-, evidence-, and practise-based interventions. For this purpose we reviewed the literature, performed two focus group interviews with the target population of visually impaired elderly persons (n=8 and n=9), performed a focus group interview with delegates of interest groups for blind and visually impaired people (n=7), organized an expert meeting with health professionals involved in low-vision rehabilitation, researchers and visually impaired elderly persons (n=9), and examined determinants of participation [33]. Subsequently, the results guided the development and design of the *VIPP*-programme. In consultation with the physical therapist, occupational therapists and social workers of the low-vision rehabilitation centre involved, a programme manual was written. The program aims to enhance participation in society by improving practical skills, promoting adaptation to the visual impairment, and improving physical fitness.

VIPP is a 20-week programme consisting of structured weekly group sessions (duration 2 hours) and a booster session 12 weeks after the completion of the programme. The *VIPP*-programme consists of four components: 1) training of practical skills; 2) education, social interaction, and counselling and training of problem-solving skills; 3) individual and group goal-setting; and 4) a home-based physical exercise programme. The structured sessions start with 60 minutes of practical training by two occupational therapists. After a 15-minute break a social worker continues with a 45-minutes education and counselling session. During the first session, an exercise coach introduces simple physical exercises and a graded walking programme. Additionally, the exercise coach delivers counselling by means of 12 telephone conversations throughout the programme according the principles of motivational interviewing [36,37]. The progress, benefits and difficulties of physical activity as perceived by the subjects are being discussed. Table 6.1 gives an overview of the topics within each of the four components. The sessions were conducted in small groups that contained sufficient participants to enable social interaction but had a maximum of nine participants to ensure safety within the practical training component. Because of the relatively long duration

of the *VIPP*-programme and the potential problems with transport, we aimed to deliver the programme within the vicinity of the study participants, i.e. at two locations of the low-vision rehabilitation centre as well as two rural locations. This resulted in a group size that varied from 4 to 9 participants. All supervisors of the programme were trained before the start of the intervention. Detailed information of the intervention programme can be obtained with the first author (MAA).

6.2.4 Measures

Participation was assessed with the Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P-version 8) [38]. This instrument, which is based on the ICF, assesses three aspects of participation (i.e. frequency, restrictions and satisfaction) and covers vocational activities (i.e. paid work, unpaid work, study, housekeeping), leisure activities and social activities. The frequency scale assesses the number of hours weekly spend on vocational activities on a scale from 0 (not at all) to 5 (36 hours or more) and assesses the frequency of performing eight leisure and social activities (scale from 0 [not at all] to 5 [19 times or more]). The restriction scale assesses restrictions as a result of the health condition (i.e. visual impairment) in 10 activities on a scale from 0 (not possible at all) to 3 (no difficulty at all). A 'not applicable' option is available if subjects are not involved in the activity or if subjects experience restrictions due to other causes than the visual impairment. The satisfaction scale asks persons to rate their satisfaction on a scale from 0 (very dissatisfied) to 4 (very satisfied) and was based on the six items that addressed participation (i.e. work/ housekeeping, leisure outdoors, leisure indoors, partner relationship, family relationships, friends and acquaintances). A 'not applicable' option is available for the items 'work/ housekeeping' and 'partner relationship'. All item- and scale-scores were standardized to a 0 to 100 scale. Higher scores indicate higher levels of participation, less participation restrictions and more satisfaction with participation, respectively. The psychometric properties of the USER-P were described as satisfactory [38-40].

Autonomy in participation was assessed with the outdoors subscale of the Impact on Participation and Autonomy questionnaire (IPA)[41]. Five items are rated on a scale from 0 (very good) to 4 (very poor). The scale-score is calculated by taking the mean score of the items. A higher score indicates less autonomy. The IPA is a reliable and valid instrument [42].

Table 6.1: Overview of the topics within each of the four components of the multidisciplinary group rehabilitation programme *VIPP*

Training of practical skills	**Education, social interaction, and counselling and training of problem-solving skills**	**Individual and group goal- setting**	**Home-based physical exercise programme**
Orientation and mobility (O&M): - aids and devices for O&M - O&M in and around home - O&M as a pedestrian - using public transport - finding your way in public areas/ buildings - compensatory use of other senses *Participation:* - shopping - leisure and recreation	*Education:* - basic anatomical structure of the eye and eye diseases - services and supports available for visually impaired people *Social interaction:* - sharing experiences: ▪ emotional impact (dependency, society's expectations) ▪ coping strategies *Counselling and training of problem-solving skills:* - asking for assistance - explaining vision loss to others - recognizing body language and communication with others - energy balance	*Goal-setting and action planning* *Individual:* - identifying personal goals - making an action plan - feedback on action plan and discussing progress - examples: ▪ using public transport ▪ visiting a concert/museum ▪ joining a fitness club ▪ shopping independently *Identifying group goals:* - examples: ▪ fall prevention ▪ visiting a fitness club ▪ playing card and board games ▪ making a forest walk	*Home based physical exercise:* - graded step-by-step walking programme - physical exercises 3x per week *Telephone counselling by exercise coach:* - 12 scheduled conversations - evaluating progress walking programme and physical exercises - discussing benefits of being physically active - discussing barriers and perceived difficulties

6.2.5 Statistical analysis

Data were analysed using SPSS version 16.0 (SPSS Inc., Chicago IL., USA). Non-response analysis was performed with Student's *t*-test and Chi-square tests.

The effect of the *VIPP*-programme on the outcome measure of participation was tested at scale-level as well as at item-level in order to get insight in the effect on separate items of the participation measures. At scale-level, the effect was tested with the one-way repeated measures ANOVA. Level of significance (*P*) was set on 0.10 because of the small sample size. In addition to statistical testing, the eta squared (η^2) is reported, which is a measure of the effect size for use in ANOVA and expresses the proportion of variance in participation explained by the intervention. An eta squared of 0.01 is equal to 1% of explained variance and constitutes a small effect, 6% a medium effect, and 14% a large effect [43]. For exploratory purposes a post-hoc procedure was performed (i.e. contrast tests; contrast simple [reference first and last]) to get insight if effects occurred during the intervention period or in the follow-up period.

To test the effect of the intervention at item-level we performed the non-parametric Friedman's analysis of variance (Friedman's ANOVA). *P* was set on 0.05 which is more conservative in comparison than the *P* value applied on the one-way repeated measures ANOVA because of multiple testing. The Wilcoxon signed-rank test was used as a post-hoc procedure to test for differences between the three time points. The ES (r) on item-level was calculated by dividing the Z-statistic of the Wilcoxon signed-rank tests by the square root of the total number of observations [44]. An ES (r) of 0.10 constitutes a small effect, 0.30 a medium effect and 0.50 a large effect [43].

6.3 Results

Twenty-nine visually impaired persons started with the *VIPP*-programme. Three persons (10%) withdrew from the study after the first session (mean age 71.3 years; 33% female; mean visual acuity 0.47logMAR). Descriptive characteristics at baseline of subjects who completed the *VIPP*-programme (n=26) are shown in Table 6.2. Subjects who withdrew from the study had average scores on participation frequency (mean 33.3), restrictions (mean 62.0), and satisfaction (mean 65.7), although there was a tendency for less autonomy (mean 1.9). We did not test for differences between those who completed the study and those who withdrew because of the small number.

Table 6.2: Descriptive characteristics of the study population at baseline (n = 26)

Characteristic	Value – n (%)[a]
Age, years	
Range	57 – 88
Mean±SD	73.2 ± 8.0
Gender, female	18 (69)
Partner status, partner	12 (46)
Educational level[b]	
(Pre)Primary	5 (19)
Lower secondary	13 (50)
Upper secondary	6 (23)
Tertiary	2 (8)
VFQ-25[c]	
Fair	6 (23)
Poor	11 (42)
Very poor	6 (23)
Completely blind	3 (12)
Binocular visual acuity (VODS)	
Median	0.20
Mean±SD (logMAR[d])	0.88 ± 0.73
Duration of visual impairment, years	
Range	3 – 59
Median	8.5
Primary cause of visual impairment	
Age-related maculopathy	14 (54)
Vascular disorders[e]	2 (8)
Optic nerve disorders	1 (4)
Congenital and hereditary disorders[f]	1 (4)
Trauma	1 (4)
Cause unknown	3 (12)
Combination of causes	4 (15)
Co-morbidity	
0	4 (15)
1	14 (54)
≥2	8 (31)
Type of co-morbid conditions	
Diabetes mellitus	6 (23)
Osteoarthritis	7 (27)
Diseases of the respiratory system	2 (8)
Other chronic conditions[g]	17 (65)
Diabetes mellitus	6 (23)

[a] Percentages are based on totals for each category, and may not total 100 because of rounding
[b] International Standard Classification of Education (ISCED) [52]
[c] Visual Functioning Questionnaire [53]: "At the present time, would you say your eyesight using both eyes (with glasses or contact lenses) is excellent, good, fair, poor, very poor or are you completely blind?"
[d] LogMAR value: –log visual acuity
[e] e.g. diabetic retinopathy
[f] e.g. retinitis pigmentosa
[g] e.g. diseases of the circulatory system, rheumatoid arthritis, diseases of the vestibular system, neurological disorders

Six subjects (23%) attended all 20 sessions of the programme. Three subjects (12%) missed one session, 15% (n=4) missed two sessions, 19% (n=5) missed three sessions, 15% (n=4) missed four sessions, two subjects (8%) missed five sessions, one subject (4%) missed six sessions, and one subject (4%) did not attend at nine sessions. The exercise coach completed the twelve telephone conversations as planned with 50% of the subjects. Forty-six percent missed only one conversation and one subject missed two conversations (mean duration 14 minutes [SD 4.7]; range 3-46). Reasons for missing a group session or a telephone conversation were illness, holidays, interference with other appointments, or subjects could not be reached by phone.

6.3.1 Effects on participation at scale level

Table 6.3 presents the mean scores of the participation measures (i.e. frequency, restriction, satisfaction, autonomy) over time. The mean scores showed an increase in frequency in participation, satisfaction and autonomy, and a decrease in restrictions at post-test. The *P* values of the one-way repeated measures ANOVA indicated no statistical significant changes over time although the improved autonomy outdoors was of borderline statistical significance (*P*=0.11). In addition to statistical testing the eta squared values (effect sizes) were examined, which give an impression of the magnitude of the intervention effect. These values indicated small effects for restrictions in participation and satisfaction with participation (2.5% and 4.7% explained variance, respectively), and there was a medium effect for autonomy outdoors (8.5% explained variance). The post-hoc procedure was used to follow up these findings and showed that these effects occurred at post-test (T0-T1: restrictions η^2=0.042; satisfaction η^2=0.048; autonomy η^2=0.023) as well as at six-months follow-up compared to baseline (T0-T2: restrictions η^2=0.036; satisfaction η^2=0.085; autonomy η^2=0.139). For autonomy outdoors there was a medium effect during the follow-up period as well (T1-T2: η^2=0.081).

Table 6.3: Comparison of participation at pre-test (T0), post-test (T1), and at six-months follow-up (T2)

	n	T0 mean (SD)	T1 mean (SD)	T2 mean (SD)	F[a]	η^2	*P*-value
USER-P							
Frequency	26	33.0 (9.9)	33.5 (7.4)	32.4 (7.8)	0.21	0.008	0.89
Restrictions	26	65.9 (17.0)	68.9 (15.2)	69.8 (15.6)	0.65	0.025	0.53
Satisfaction	26	70.1 (13.6)	73.0 (10.3)	73.6 (12.3)	1.25	0.047	0.30
IPA							
Autonomy outdoors	26	1.26 (0.64)	1.16 (0.61)	0.99 (0.54)	2.32	0.085	0.11

[a] F-statistic (2,50) of the one-way repeated measures ANOVA
η^2 Eta squared

6.3.2 Frequency of participation at item level

Table 6.4 presents the mean scores of the items that measured frequency of participation at pre-test, post-test and six-months follow-up. The mean scores at post-test (T1) showed an increase in frequency for certain activities (i.e. unpaid work, housekeeping, going out, leisure indoors, visits to and from family or friends, and telephone/computer contacts) whereas the frequency for other activities decreased (i.e. paid work, outdoor activities, chores in/around house). Compared to baseline, the six-months follow-up mean scores suggested that study participants tended to be more engaged in outdoor activities and leisure indoors.

The Friedman's ANOVA only showed a statistical significant change for housekeeping ($p=0.029$). The post-hoc procedure indicated a small increase in housekeeping at post-test (T0-T1: ES(r)=0.18) but a small decrease at six-months follow-up compared to baseline (T0-T2: ES(r)=0.13). There was a small negative effect on housekeeping during the follow-up period (T1-T2: ES(r)=0.28).

6.3.3 Participation restrictions at item level

With respect to participation restrictions (Table 6.4) at post-test (T1), the mean scores showed a decrease in restrictions in housekeeping, outdoor activities and leisure indoors. Restrictions in physical exercise, going out, chores in/around house, visits to family and friends, and telephone/computer contact increased at post-test. Compared to baseline, the six-months follow-up indicated a decrease in restrictions in housekeeping, outdoor activities, and visits to family/friends. Comparison between post-test and six-months follow-up indicated a decrease in restrictions in physical exercise, going out and visits to family/friends, whereas restrictions in leisure indoors increased.

The change in restrictions in housekeeping and outdoor activities reached statistical significance ($p=0.038$ and $p=0.032$, respectively). The post-hoc procedure indicated a small decrease in restrictions in housekeeping at post-test (T0-T1: ES(r)=0.29) and at six-months follow-up compared to baseline (T0-T2: ES(r)=0.25). There was a medium decrease in restrictions in outdoor activities at post-test (T0-T1: ES(r)=35) and at six-months follow-up compared to baseline (T0-T2: ES(r)=0.35). Both effects occurred at post-test after completion of the intervention and maintained at six-months follow-up.

6.3.4 Satisfaction with participation at item level

The mean scores of the items that measured satisfaction with participation (Table 6.4) at post-test indicated an increase in satisfaction for all items, except for satisfaction with friends and acquaintances. Compared to baseline, the six-months follow-up measure indicated an increase in satisfaction with leisure outdoors and indoors, and with the partner relationship, whereas satisfaction with work/housekeeping decreased.

The change in satisfaction with the partner relationship reached statistical significance (p=0.015) whereas the change in satisfaction with leisure indoors was of borderline statistical significance (p=0.075). The post-hoc procedure indicated a medium increase in satisfaction with the partner relationship at post-test (T0-T1:ES(r)=0.44) and at six-months follow-up compared to baseline (T0-T2: ES(r)=0.21). There was a small increase in satisfaction with leisure indoors at post-test (T0-T1: ES(r)=0.11) and at six-months follow-up compared to baseline (T0-T2: ES(r)=0.28). Both effects occurred at post-test after completion of the intervention. Satisfaction with leisure indoors tended to increase further during the follow-up period (T1-T2: ES(r)=0.28).

6.3.5 Autonomy in participation at item level

With respect to autonomy in participation outdoors, the mean scores (Table 6.4) indicated an increase in autonomy at post-test as well as at six-months follow-up compared to baseline. Only autonomy with regard to visiting friends and relatives decreased at post-test.

The change in autonomy over time was too small to reach statistical significance although autonomy in using leisure time was of borderline statistical significance (p=0.099). The post-hoc procedure indicated a small increase in autonomy in using leisure time at post-test (T0-T1: ES(r)=0.15) and a medium effect at six-months follow-up compared to baseline (T0-T2: ES(r)=0.32). There was a trend for a further increase during the follow-up period (T1-T2: ES(r)=0.24).

Table 6.4: Comparison of frequency of performance, restrictions in, satisfaction with and autonomy in participation at pre-test (T0), post-test (T1), and at six-months follow-up (T2)

	N	T0 mean (SD)	T1 mean (SD)	T2 mean (SD)	Chi-square[a]	T0-T1 ES	T0-T2 ES	T1-T2 ES
Frequency								
Paid work	26	6.2 (22.5)	3.8 (19.6)	3.8 (19.6)	2.00	0.14	0.14	0.00
Unpaid work	26	9.2 (14.1)	10.8 (17.2)	9.2 (11.6)	0.29	0.10	0.00	0.10
Education	26	1.5 (7.8)	0.0 (0.0)	0.0 (0.0)	2.00	0.14	0.14	0.00
Housekeeping	25	39.2 (23.4)	46.4 (20.6)	36.0 (25.2)	7.08*	0.18	0.13	0.28
Physical exercise	26	76.9 (36.1)	76.2 (39.6)	71.5 (30.0)	1.03	0.02	0.09	0.13
Going out	26	13.8 (16.8)	15.4 (19.0)	14.6 (16.5)	0.29	0.08	0.06	0.04
Outdoor activities	26	33.8 (31.4)	30.8 (24.8)	38.5 (26.5)	1.09	0.03	0.11	0.19
Chores in/around house	26	36.9 (46.5)	33.1 (38.8)	38.5 (41.9)	0.22	0.06	0.01	0.07
Leisure indoors	25	68.8 (41.7)	71.2 (39.6)	77.6 (35.7)	0.68	0.03	0.18	0.11
Visits to family or friends	26	49.2 (27.8)	52.3 (23.4)	46.2 (22.5)	1.08	0.08	0.10	0.17
Visits from family or friends	26	54.6 (26.3)	56.2 (28.9)	55.4 (26.1)	0.03	0.02	0.03	0.02
Telephone/computer contact	25	82.4 (23.3)	84.8 (22.6)	78.4 (26.4)	0.52	0.09	0.08	0.13
Restrictions								
Work/education	2	66.7 (0.0)	66.7 (0.0)	83.3 (23.6)	2.00	0.00	0.50	0.50
Housekeeping	24	56.9 (23.0)	68.1 (15.5)	66.7 (19.7)	6.53*	0.29	0.25	0.05
Physical exercise	23	68.2 (30.9)	65.2 (25.6)	73.9 (24.5)	2.26	0.04	0.09	0.15
Going out	16	58.3 (33.3)	56.3 (29.1)	60.4 (25.0)	0.93	0.06	0.03	0.11
Outdoor activities	19	49.1 (30.2)	64.9 (30.4)	64.9 (28.3)	6.88*	0.35	0.35	0.00
Chores in/around house	15	73.3 (18.7)	68.9 (19.8)	66.7 (28.2)	0.84	0.13	0.15	0.05
Leisure indoors	23	53.6 (32.9)	59.4 (30.1)	50.7 (31.6)	2.27	0.11	0.05	0.18
Visits to family or friends	25	68.0 (29.6)	65.3 (32.6)	74.7 (26.0)	1.05	0.06	0.13	0.16
Visits from family or friends	23	87.0 (21.9)	88.4 (21.6)	87.0 (21.9)	0.24	0.04	0.01	0.04
Telephone/computer contact	26	93.6 (16.4)	85.9 (21.4)	88.5 (21.0)	3.35	0.18	0.13	0.07

Table 6.4 continued

	N	T0 mean (SD)	T1 mean (SD)	T2 mean (SD)	Chi-square[a]	T0-T1 ES	T0-T2 ES	T1-T2 ES
Satisfaction								
Work/housekeeping	21[b]	67.9 (17.9)	70.2 (15.0)	63.1 (23.2)	2.23	0.11	0.14	0.25
Leisure outdoors	24	61.5 (25.5)	65.6 (24.2)	70.8 (21.7)	1.65	0.09	0.22	0.15
Leisure indoors	26	53.8 (26.2)	57.7 (24.3)	65.4 (21.3)	5.18	0.11	0.25	0.28
Partner relationship	11[b]	75.0 (29.6)	90.9 (12.6)	79.5 (24.5)	8.40*	0.44	0.21	0.40
Family relationships	26	84.6 (21.3)	85.6 (17.6)	83.7 (17.2)	0.88	0.03	0.04	0.08
Friends and acquaintances	26	80.8 (22.7)	77.9 (19.1)	80.8 (16.3)	1.48	0.10	0.01	0.11
Autonomy								
Visiting friends and relatives	26	1.04 (0.53)	1.19 (0.94)	0.88 (0.71)	2.91	0.10	0.15	0.28
Going on trips and holidays	23	1.26 (0.92)	1.00 (0.74)	1.04 (0.77)	0.41	0.17	0.11	0.03
Using leisure time	26	1.46 (1.18)	1.23 (0.86)	0.88 (0.65)	4.63	0.15	0.32	0.24
Seeing people	26	1.31 (0.88)	1.15 (0.83)	1.04 (0.60)	1.44	0.09	0.21	0.09
Living life	26	1.19 (1.06)	1.15 (0.78)	1.08 (0.74)	0.34	0.04	0.09	0.09

[a]Degrees of freedom of the Chi-square are 2;
[b]The 'not applicable' response option applies to this item;
*p<.05

6.4 Discussion

The purpose of this pilot study was to investigate the impact of a multidisciplinary group rehabilitation programme for the visually impaired elderly (*VIPP*) on four aspects of participation: frequency of performance, restrictions, satisfaction and autonomy outdoors. With respect to the scale scores, no statistical significant changes over time were found although autonomy outdoors tended to improve. The explained variance in participation that the intervention accounted for suggest small effects for restrictions and satisfaction, and a medium effect for autonomy outdoors. At item level, small to medium improvements tend to occur in performance of housekeeping, in restrictions in housekeeping and outdoor activities, and in satisfaction with the partner relationship, whereas satisfaction with leisure indoors and autonomy regarding using leisure time tend to increase. Our tentative conclusion from this small-scale pilot study is that the *VIPP*-programme modestly benefits perceived restrictions in participation, satisfaction with participation and autonomy outdoors. These preliminary findings warrant further research.

The *VIPP*-programme was designed to enhance the level of participation in society. The results showed only a modest increase in housekeeping whereas participation in other activities did not change. Evans et al. [24] also found an increase in the level of household activity whereas involvement in social activities, including activities outside, remained stable. The studies of Packer et al. [25] and Girdler et al. [26] reported a 5-8% increase in the total number of activities as an effect of a vision self-management programme. This partial effect was also found by Brody et al. [29]: participation in some activities increased whereas participation in other activities decreased. Although we did not find an increase in the frequency of participation, we did find positive effects on subjective aspects of participation. The results of our study suggest a small improvement in perceived restrictions in participation which is in accordance with the studies of Lamoureux et al. [27] and Birk et al. [28]. The modest improvement in autonomy outdoors is in line with the findings of Birk et al. [28] who showed the benefits of a psychosocial intervention. As far as we know, no studies examined satisfaction with participation in low-vision rehabilitation before and the tendency of increased satisfaction with participation we found can be regarded as a novelty.

The intervention mapping development procedure [34,35] resulted in a multidisciplinary group rehabilitation programme that consists of components previously described in low-vision rehabilitation interventions [24-30,45,46]. Similar to psychosocial [28] and self-management interventions [25,26,29,46], *VIPP* is a group-based programme. Identification with other people with the same visual problems provides the opportunity to share experiences and coping strategies on both functional and emotional issues [31]. In addition, the group enhances social interaction and offers the opportunity for social support [31,47]. Besides the added value of group learning, the *VIPP*-programme incorporated

an individual component. Individual goal-setting enhances a person's motivation and is a useful strategy for actively assisting visually impaired persons in their search for meaningful goals [31,48,49]. The *VIPP*-programme has a multidisciplinary approach referring to the multidimensional learning process of the visually impaired. They have to acquire new skills and have to change their behaviour patterns in addition to grieving the loss of normal vision and the emotional shift from being a normally sighted to being a visually impaired person [45]. Therefore, the *VIPP*-programme includes training of practical skills by occupational therapists as well as education, counselling and training of problem-solving skills by social workers. In addition, a physical exercise component was included to improve physical fitness which is a determinant of participation [5,33]. To our knowledge, the *VIPP*-programme is the first group-based multidisciplinary low-vision rehabilitation intervention that combines individual goal-setting and physical exercise.

Because of the multidisciplinary structure, the *VIPP*-programme has a relatively long duration (20 weeks) in comparison with other low-vision rehabilitation interventions. It is recommended that low-vision rehabilitation interventions should be as short as possible because of the problems visually impaired persons have with transportation [28]. Our study, however, showed that only 7% of those interested in the *VIPP*-programme declined to participate because of this reason. Furthermore, the low drop-out rate (10%) indicates that the duration of the *VIPP*-programme was not a barrier for attending the programme although the percentage of non-attendance was substantial. It is likely that interventions with a relatively long duration more often are confronted with non-attendance, for example due to illness or participants holidays, hospital visits etc. The *VIPP* study participants expressed that they had no problem with the long duration as assessed in an evaluation session. The occupational therapists and social workers, however, had the opinion that the number of group sessions could be reduced to 12 sessions, if the duration of each session should be extended to 2.5 hours. This may reduce the non-attendance rate. A drawback of rehabilitation programmes with a long duration is the additional costs. Future research has to show if the *VIPP*-programme is economically feasible.

To our knowledge, this is the first study that assessed the effect of low-vision rehabilitation on four aspects of participation: frequency, restrictions, satisfaction and autonomy. Although we did not find an effect for the frequency of participation (performance), we did find small positive effects for restrictions and satisfaction and a medium effect for autonomy. These results suggest that it is imperative to make a distinction between these aspects of participation. This is also confirmed by the literature [50,51] that showed that the objective (performance frequency) and subjective (restrictions, satisfaction and autonomy) aspects represent different constructs evidenced by the weak correlation. The content of the programme was based on the ICF and aimed to enhance participation in domestic life, interpersonal interactions and relationships, major life areas, and community,

social and civic life. The outcome measure USER-P reflects these ICF components. The *VIPP*-programme is as far as we know the first low-vision rehabilitation intervention that combines a multidisciplinary group intervention with an individual goal-setting component and a home-based exercise programme. Another strength of the study is that visually impaired elderly persons and professionals from the low-vision service provider were involved in the development of the *VIPP*-programme. This ensured that the programme was practise-based. The programme was delivered by experienced low-vision professionals within the setting of a low-vision rehabilitation provider which enabled the feasibility of the *VIPP*-programme. The low drop-out indicates the acceptability of the *VIPP*-programme. The substantial non-attendance, however, indicates that revision of the programme towards a shorter duration is needed.

The results of this pilot study should not be interpreted without taking some limitations into account. The small sample size limited the statistical power which may account for the lack of statistical significance despite the small and medium effect sizes that were found. The pre-test post-test study design, which has a limited level of evidence compared to a randomized controlled design, complicates the interpretation of the findings. The lack of a control group makes it difficult to draw conclusions whether the tentative effects were caused by the intervention or by other factors such as seasonal influences. Concerning the generalizability of our findings to the Dutch population of the visually impaired elderly, it should be noted that the present study included visually impaired elderly persons who were referred to and registered at a low-vision rehabilitation centre. This recruitment procedure may implicate a selection of a subgroup of the visually impaired elderly, i.e. those who are motivated to seek rehabilitation. The inclusion of elderly with a low level of participation may imply regression towards the mean. The modest effects on the USER-P we found may be explained by the fact that at the individual level large score differences are required to exceed change [38]. Lastly, the data on the outcome measures are self-report data which may implicate a social desirability bias.

To conclude, this small-scale pilot study is a first step towards documenting the effectiveness of the multidisciplinary group rehabilitation programme *VIPP* on participation of the visually impaired elderly. Although the findings are preliminary because of the small sample size and research design, the results of this pilot indicate that the *VIPP*-programme suggests small to medium effects on the subjective aspects of participation. Future research is needed to offer further evidence on the effectiveness of the *VIPP*-programme among larger study populations using controlled designs using waiting-list or care-as-usual control groups. Furthermore, an analysis of the costs of this rehabilitation programme relative to the benefits would provide further evidence of its efficiency.

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7

Effects of the multidisciplinary group rehabilitation program *Visually Impaired elderly Persons Participating* on aerobic endurance and functional mobility of the visually impaired elderly: a pilot study

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ABSTRACT

Purpose: This study aims to examine the effects of the multidisciplinary group rehabilitation program *Visually Impaired elderly Persons Participating (VIPP)* on aerobic endurance and functional mobility of the visually impaired elderly.

Methods: Twenty-nine visually impaired elderly persons (≥55 years) who were referred to a low-vision rehabilitation center according to the Dutch guidelines participated in this single group pre-test post-test study. The multidisciplinary group rehabilitation program *VIPP* consisted of four components: 1) practical training; 2) education, social interaction, counseling and training of problem-solving skills; 3) individual and group goal-setting; and 4) a home-based physical exercise program with telephone coaching. The program consisted of 20 weekly sessions. The 2-minute step test and the Timed Up and Go test (TUG) were used to assess aerobic endurance and functional mobility at baseline (T0), halfway (T1), immediately after the completion of the intervention (T2), and at 6-months follow-up (T3).

Results: Compared to baseline (T0), aerobic endurance had improved halfway the program (T1), immediately after the completion of the program (T2) and at 6-months follow-up (T3) ($p=0.02$; $p=0.007$ and $p=0.002$, respectively). The corresponding effect-sizes were large (ES=0.50; ES=0.58 and ES=0.66, respectively). Compared to baseline, functional mobility had improved at T1 and T3 ($p<0.001$ and $p=0.001$). The effect-sizes were large (ES=0.57 and ES=0.50). There was no statistically significant improvement in functional mobility at T2 when compared to baseline ($p=0.06$), although it was a medium effect (ES=0.30).

Conclusion: The results of this pilot study show that participation in the multidisciplinary group rehabilitation program *VIPP* leads to an increase in aerobic endurance and functional mobility in the visually impaired elderly. From previous research it is known that the visually impaired elderly have a lower level of aerobic endurance compared to peers. Therefore, it is important to offer visually impaired elderly persons the opportunity to participate in *VIPP*.

7.1 Introduction

In 2008, 79% of the visually impaired persons in the Netherlands were aged 65 years and over [1]. Due to aging of the population, the total number of visually impaired elderly people is expected to increase [1]. Blindness is defined as visual acuity <0.05 in the better eye with the best correction possible or a corresponding visual field <10 degrees [2]. Low vision is defined as visual acuity <0.3 but ≥0.05, or a corresponding visual field <30 degrees but ≥10 degrees [2]. Vision loss may lead to psychosocial problems, such as depressive feelings [3-5], and has a negative impact on quality-of-life [6,7]. In addition, vision loss may lead to social isolation [8], loneliness [9,10] and disability [11,12]. Visually impaired elderly people perceive difficulties in performing activities [6,13,14] and participate less in household activities, recreational activities and sports activities compared to peers [15].

Since the development of the International Classification of Functioning, Disability and Health (ICF)[16] by the World Health Organization, the concept of participation has become of interest as an outcome measure of health. The ICF is a multipurpose classification for the description of health and health-related states, and defines participation as "involvement in life situations" [16]. According to the literature, participation is associated with a reduced risk of functional [17] and cognitive [18] decline, and has a positive influence on quality-of-life and well-being [19,20]. Since the visually impaired elderly perceive restrictions in participation [15,21] and participate less in society compared to peers [15], it is important that visually impaired elderly persons maintain or enhance their level of participation. This can be accomplished by influencing the determinants of participation. The study of Alma et al. [22] showed that physical fitness is associated with participation. This association between physical fitness and participation was also found by Anaby et al. [23] and Lamoureux et al. [24]. Besides physical fitness, other factors are associated with participation such as partner status, social network size, mental health, helplessness and self-management abilities [22]. These studies underline the importance of a multidisciplinary approach in low-vision rehabilitation. Therefore, the improvement of physical fitness should be one of the components of low-vision rehabilitation.

Physical fitness is a "multidimensional" concept and is defined as "the extent to which the elderly have the disposition of motor skills that are necessary to perform and maintain motor action of daily living" [25]. Physical fitness comprises of several components: aerobic endurance, functional mobility, coordination, agility, balance, flexibility and muscular strength. In this study, we focus on aerobic endurance and functional mobility. Aerobic endurance is defined as "the ability to sustain large-muscle activity over time" [26]. Functional mobility is defined as "the mobility that is necessary to perform activities of daily living" [26].

A previous study of our research group showed that aerobic endurance of the visually impaired elderly is poor compared to the aerobic endurance of peers [27]. Jones et al. [28] found that the visually impaired elderly are more often physically inactive than the normally sighted elderly. In addition, the visually impaired elderly perceive more mobility restrictions [14]. A study among elderly persons diagnosed with age-related macular degeneration showed that vision loss is associated with musculoskeletal problems [29]. Considering the results of the afore cited studies and the association between physical fitness and participation [22-24], it is important that the visually impaired elderly improve their aerobic endurance and functional mobility.

To our knowledge, there are no studies that investigated the effectiveness of a multidisciplinary group rehabilitation program on aerobic endurance and functional mobility among the visually impaired elderly. In a previous study, we described the development of the multidisciplinary group rehabilitation program *Visually Impaired elderly Persons Participating (VIPP)* [30]. This program aims to enhance the degree of participation by improving practical skills, promoting adaptation to the visual impairment, and improving physical fitness. In the present study, we investigated the impact of *VIPP* on physical fitness (i.e., aerobic endurance and functional mobility). We expect that the *VIPP*-program, which includes physical exercise, has a positive effect on physical fitness.

7.2 Methods

7.2.1 Study population

In November 2008, 134 visually impaired elderly clients (≥ 55 years) of Royal Dutch Visio (region North Netherlands) were invited to participate in the study. These study participants originated from a previous cross-sectional study on participation of the visually impaired elderly (n=173)[15,22]. Participants of this cross-sectional study were eligible for the present study if they had a low level of outdoor participation. Additional inclusion criteria were: 1) aged ≥ 55 years; 2) able to walk (with or without a walking aid); and 3) referred to a low-vision rehabilitation center according to the Dutch guidelines [31]. According to these guidelines, persons with a visual acuity <0.3 and/or a visual field <30 degrees should be referred to a low-vision rehabilitation center. In addition, persons with a visual acuity between 0.3 and 0.5, and who perceive vision-related problems in daily life, should also be considered for referral to low-vision rehabilitation. Those 134 visually impaired elderly persons received information about *VIPP* by mail. By returning a reply card, participants could indicate whether they were interested to cooperate. Of these 134 participants, 43 (32%) were interested and received detailed information about *VIPP* by phone. Twenty-nine visually impaired elderly persons gave informed consent and finally participated in the study. Figure 7.1 shows a flow diagram of the inclusion of the study participants. Non-response analysis showed no

differences between the study participants (n=29) and non-responders (n=87) with respect to age (t=-0.92; p=0.36), gender (chi-square=0.43; p=0.51), partner status (chi-square=0.004; p=0.95), binocular visual acuity (t=0.48; p=0.63), and co-morbidity (z=-0.42; p=0.67).

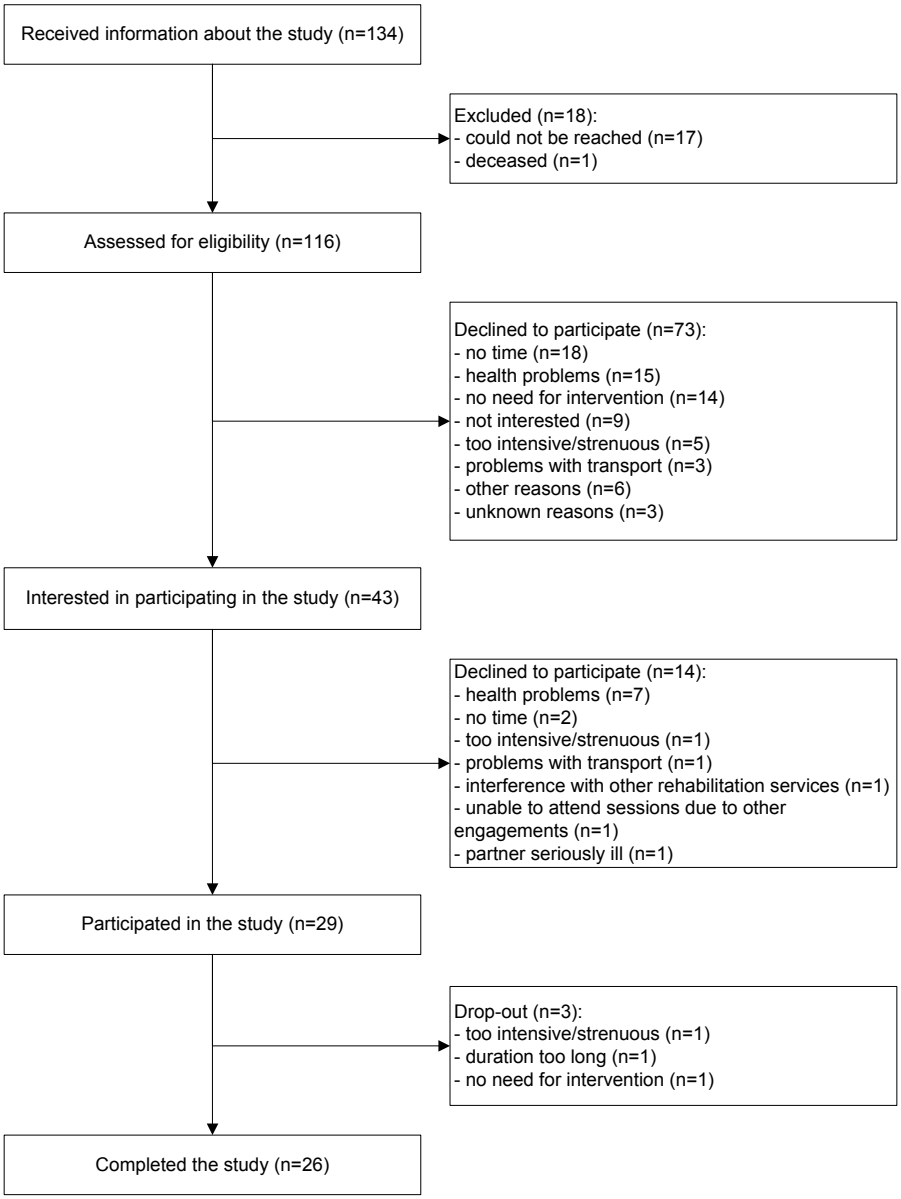

Figure 7.1: Flow diagram of inclusion of the study subjects

7.2.2 Design

This pilot study had a single group pre-test post-test design. Data were collected by field-based assessments of physical fitness at baseline (T0), halfway through the intervention (T1), immediately after the completion of the intervention (T2), and at 6-months follow-up (T3). All subjects provided written informed consent before the start of the intervention. The study followed the tenets of the Declaration of Helsinki and The Medical Ethics Committee of the University Medical Center Groningen reviewed the study protocol.

7.2.3 Intervention: Visually Impaired elderly Persons Participating

Visually Impaired elderly Persons Participating (VIPP) is a multidisciplinary group rehabilitation program for the visually impaired elderly which is developed according to the principles of intervention mapping [32]. Intervention mapping is a stepwise procedure for developing theory-, evidence-, and practice-based interventions. The content of *VIPP* is based on a cross-sectional study on determinants of participation [22], two focus group interviews with visually impaired elderly persons (n=8 and n=9), a focus group interview with delegates of interest groups for blind and visually impaired people (n=7), an expert meeting with researchers, health professionals involved in low-vision rehabilitation and visually impaired elderly persons (n=9), and a review of the literature. In consultation with the physical therapist, occupational therapists and social workers of Visio, a program manual was written. *VIPP* aims to enhance participation in society by improving practical skills, promoting adaptation to vision loss and improving physical fitness.

VIPP is a multidisciplinary group rehabilitation program consisting of four components: 1) training of practical skill; 2) education, social interaction, and counseling and training of problem-solving skills; 3) individual and group goal-setting; and 4) a home-based exercise program with telephone coaching. Table 7.1 gives an overview of *VIPP*. The program consists of 20 structured weekly group sessions (duration 2 hours) and a booster session 12 weeks after the completion of the program. The structured sessions start with 60 minutes of practical training by two occupational therapists. Within this component, the following topics are addressed: orientation and mobility (O&M) in and around home, aids and devices for O&M, O&M as a pedestrian, finding the way in public areas, using public transport, compensatory use of other senses, and leisure and recreation (e.g., visiting a fitness club). After a 15-minute break a social worker continues with a 45-minute education and counseling session. Within this component of the program, the following topics are addressed: basic anatomical structure of the eye and eye diseases, volunteers, available services and support, coping with society's expectations, (in)dependency, energy balance, and body language.

Table 7.1: Overview of the topics within each of the four components of the *VIPP*-program.

Training of practical skills	Education, social interaction, and counselling and training of problem-solving skills	Individual and group goal- setting	Home-based physical exercise programme
Orientation and mobility (O&M): - aids and devices for O&M - O&M in and around home - O&M as a pedestrian - using public transport - finding your way in public areas/buildings - compensatory use of other senses *Participation:* - shopping - leisure and recreation	*Education:* - basic anatomical structure of the eye and eye diseases - services and supports available for visually impaired people *Social interaction:* - sharing experiences: ▪ emotional impact (dependency, society's expectations) ▪ coping strategies *Counselling and training of problem-solving skills:* - asking for assistance - explaining vision loss to others - recognizing body language and communication with others - energy balance	*Goal-setting and action planning* *Individual:* - identifying personal goals - making an action plan - feedback on action plan and discussing progress - examples: ▪ using public transport ▪ visiting a concert/museum ▪ joining a fitness club ▪ shopping independently *Identifying group goals:* - examples: ▪ fall prevention ▪ visiting a fitness club ▪ playing card and board games ▪ making a forest walk	*Home based physical exercise:* - graded step-by-step walking programme - physical exercises 3x per week *Telephone counselling by exercise coach:* - 12 scheduled conversations - evaluating progress walking programme and physical exercises - discussing benefits of being physically active - discussing barriers and perceived difficulties

In addition, *VIPP* contains a home-based exercise program. This exercise program aims to change the lifestyle of the participants by encouraging them to become more physically active. The exercise coach delivers coaching by means of 12 telephone conversations throughout the program according to the principles of motivational interviewing [33]. During the first group session, the exercise coach introduces three simple physical exercises and a graded walking program, which is shown in Table 7.2. Each participant starts this walking program at the level that corresponds with the current exercise behavior. In this way, the program will be feasible and participants will not become demotivated by a too strenuous program. During the first telephone conversation, the exercise coach and the participant discuss which grade should be the individual goal for the walking program. The simple physical exercises comprise exercises for flexibility, balance and posture, which are easy and safe to perform. The exercise coach advices participants to perform these exercises three times a week. During the following telephone conversations, the progress with respect to the graded walking program and the performance of the simple exercises are being discussed. In addition, the benefits and the difficulties of becoming more physically active as perceived by the study participant are topics for discussion and ultimately aim to change the exercise behavior of the study participants.

Table 7.2: Graded walking program

Grade	Times a week	Duration (minutes)
1	2	10
2	2	15
3	3	15
4	2	20
5	3	20
6	2	25
7	3	25
8	2	30
9	3	30
10	2	35
11	3	35
12	2	40
13	3	40
14	2	45
15	3	45
16	2	50
17	3	50
18	2	55
19	3	55
20	2	60
21	3	60
22	4	60
23	5	60
24	3	65
25	3	70

The group sessions were conducted in small groups that contained sufficient participants to enable social interaction. Because of the relatively long duration of *VIPP* and the potential problems with transport, we aimed to deliver the program within the vicinity of the study participants, i.e., at two locations of Visio (Haren and Leeuwarden) as well as at two rural locations (Drachten and Emmen). This resulted in a group size that varied from 4 to 9 participants. All supervisors of the program were trained before the start of the intervention. Detailed information of the intervention program can be obtained by the authors (MAA).

7.2.4 Measures

Aerobic endurance was measured with the 2-minute step test [26]. In two minutes, participants have to make as many steps as possible. Both knees must be raised alternately to the minimum knee-stepping height, which is at a level that is even with the midway point between the kneecap and the front hip bone (iliac crest). The score on this test is the number of times the right knee reaches the proper height. The 2-minute step test is a reliable and valid test for the elderly population [26]. A previous pilot study showed that this test is feasible for the visually impaired elderly [34].

The Timed Up and Go test (TUG) [26] was used to assess *functional mobility*. On the starting signal the participant stands up from a chair and walks a distance of 3 meters around the side of a cone, returns to the chair and sits down as quickly as possible. This test was administered twice and the fastest time was selected as the test score. The TUG is a reliable test [35] and is feasible for the visually impaired elderly population [34].

7.2.5 Analyses

Data were analyzed using Statistical Package for the Social Sciences (SPSS, version 16.0). Non-response analysis was performed with Student's t-tests, Mann-Whitney U-tests and Chi-square tests.

The Shapiro Wilk test was used to test if the data of the outcome measures were normally distributed. These tests showed that the data with respect to aerobic endurance were normally distributed, but that data considering functional mobility were skew. In order to test the effect of *VIPP* on aerobic endurance, we performed a one-way repeated measures analysis of variance (ANOVA) with contrast tests (contrast repeated and simple [reference first]). The non-parametric Friedman's ANOVA was used to test the effect of *VIPP* on functional mobility, with the Wilcoxon signed-rank test as a post-hoc procedure. Level of statistical significance was set on 0.05.

In addition to statistical testing, we computed effect-sizes (ES). The ES of aerobic endurance were calculated by the square root of the F-statistic fraction of the contrast test divided by the sum of this F-statistic and the degrees of freedom of the residuals [36]. For functional mobility, the ES was calculated by dividing the Z-statistic of the Wilcoxon signed-

rank test by the square root of the total number of observations [36]. An ES (r) of 0.10 constitutes a small effect, 0.30 as a medium effect and 0.50 as a large effect [37].

Due to physical complaints (i.e., low back pain, COPD), not every study participant was able to perform the field-based assessments at all four measurements. Consequently, only the data of those who performed the four field-based performance tests were included in the ANOVA-analyses. Nineteen participants performed the 2-minute step test at all measurements and 20 participants performed the TUG at all measurements.

7.3 Results

7.3.1 Study population

Twenty-nine visually impaired persons started with *VIPP*. Three persons (10%; 2 men, 1 woman; mean age 71.3 years) withdrew from the study after the first session (Figure 7.1). Descriptive characteristics at baseline of subjects who completed the program (n=26) are shown in Table 7.3.

Six subjects (23%) attended all 20 sessions of the program. Three subjects (12%) missed one session, four subjects (15%) missed two sessions, five subjects (19%) missed three sessions, four subjects (15%) missed four sessions, two subject (8%) missed five sessions, one subject (4%) missed six sessions, and one subject (4%) did not attend at nine sessions. The exercise coach completed the twelve telephone conversations as planned with 50% of the subjects. Forty-six percent (n=12) missed only one conversation and one subject (4%) missed two conversations. The duration of the conversations varied from 3 to 46 minutes with a mean of 14 minutes (SD 4.7). Reasons for missing a group session or a telephone conversation were illness, holidays, interference with other appointments, or subjects could not be reached by phone.

7.3.2 Aerobic endurance

Table 7.4 presents the mean scores of the 2-minute step test and the results of the ANOVA analysis. At baseline, the mean score was 51.2 (SD 16.1) steps. Compared to baseline, aerobic endurance increased statistically significant half-way the intervention (T1; p=0.02), immediately after completion of the intervention (T2; p=0.007) and at six-months follow-up (T3; p=0.002). The corresponding effect sizes were large (T0-T1: ES=0.50; T0-T2: ES=0.58 and T0-T3: ES=0.66). The small increase (ES=0.13) in aerobic endurance between T1 and T2 was not statistically significant (p=0.22). During the six-months follow-up period (T2-T3), a statistically significant increase in aerobic endurance was found (p=0.04; ES=0.45).

Table 7.3: Demographic and clinical characteristics of the study population (n =26)

Characteristic	Value – n (%)[a]
Age, years	
Mean±SD	73.2 ± 8.0
Gender, female	18 (69)
Partner status, partner	12 (46)
VFQ-25[b]	
Fair	6 (23)
Poor	13 (50)
Very poor	6 (23)
Completely blind	2 (8)
Binocular visual acuity (VODS)	
Median	0.20
Mean ± SD (logMAR[c])	0.88 ± 0.73
Primary cause of visual impairment	
Age-related macular degeneration (AMD)	14 (42)
Vascular disorders[d]	2 (8)
Optic nerve disorders	1 (4)
Combination of causes	4 (15)
Cause unknown	3 (12)
Co-morbidity	
0	4 (15)
1	14 (54)
2	8 (31)
Type of co-morbid conditions	
Diabetes mellitus	6 (23)
Osteoarthritis	7 (27)
Other chronic conditions	19 (73)

[a] Percentages are based on totals for each category, and may not total 100 because of rounding
[b] Visual Function Questionnaire – 25 [43] : "At the present time, would you say your eyesight using both eyes (with glasses or contact lenses) is excellent, good, fair, poor, very poor or are you completely blind?"
[c] LogMAR value: -log visual acuity
[d] e.g., diabetic retinopathy

Table 7.4: Mean scores and comparison of aerobic endurance (n=19) and functional mobility (n=20) at pre-test (T0), half-way (T1), immediately after completion of the intervention (T2), and at six-months follow-up (T3)

Outcome	T0 mean (SD)	T1 mean (SD)	T2 mean (SD)	T3 mean (SD)	ANOVA Test-statistic[c]	T0 – T1 ES (Test-statistic[d])	T0 – T2 ES (Test-statistic[d])	T0 – T3 ES (Test-statistic[d])	T1 – T2 ES (Test-statistic[d])	T2-T3 ES (Test-statistic[d])
Aerobic endurance[a]	51.2 (16.1)	62.6 (19.6)	64.3 (18.7)	72.6 (26.9)	8.35***	0.50 (6.07*)	0.58 (9.29**)	0.66 (13.80**)	0.13 (0.32)	0.45 (4.61*)
Functional mobility[b]	13.2 (8.0)	9.4 (4.9)	10.4 (5.4)	9.7 (5.2)	21.18***	0.57 (-3.58***)	0.30 (-1.88)	0.50 (-3.19**)	-0.14 (-0.88)	0.17 (-1.07)

[a] A higher score indicates more aerobic endurance
[b] A lower score indicates more functional mobility
[c] Aerobic endurance: F-statistic (3,54); Functional mobility: Chi-square (df=3)
[d] Aerobic endurance: F-statistic (1,18) of the contrast tests; Functional mobility: Z-statistic of the Wilcoxon signed rank test
*p<0.05; ** p<0.01; ***p<0.001

7.3.3 Functional mobility

Table 7.4 also presents the mean scores of the TUG and the results of the Friedman's ANOVA analysis. Mean score at baseline (T0) was 13.2 (SD 8.0) seconds. Compared to baseline, functional mobility increased half-way the intervention (T1) ($p<0.001$) and the corresponding effect size is large (ES=0.57). During the second half of the intervention (T1-T2), we found a small decrease in functional mobility (ES=0.14), which was not statistically significant (p=0.38). Compared to baseline, a moderate increase in functional mobility was found immediately after the completion of the intervention (T0-T2: p=0.06; ES=0,30). During the six-months follow-up period (T2-T3), we found a small increase in functional mobility (ES=0.17), which resulted in a statistically significant increase in functional mobility at six-months follow-up compared to baseline (p=0.001). The corresponding ES is large (ES=0.50).

7.4 Discussion

The purpose of the present study was to investigate the effect of the multidisciplinary group rehabilitation program *VIPP* on aerobic endurance and functional mobility of the visually impaired elderly. Although the findings are preliminary because of the study design and the small sample size, the results indicate that the multidisciplinary group rehabilitation program VIPP is favorable to both aerobic endurance as well as functional mobility.

The increase in aerobic endurance is a relevant finding, since a previous study showed that the aerobic endurance of the visually impaired elderly is poor compared to the aerobic endurance of peers [27]. Aerobic endurance of study participants increased not only during the program but also after completion of the intervention. The increase in aerobic endurance during the six-months follow-up (T2-T3) was even larger than during the second half of the program (T1-T2). It is likely that this may not only be explained by the effect of the physiological training but also by a continuation of the change in physical activity behavior. An important aim of *VIPP* is to encourage participants to become more physically active. In order to reach this goal, an exercise coach provided support by means of motivational interviewing [33]. This technique intends to improve intrinsic motivation in order to change physical activity behavior. The results of our study indicate that this aim has been achieved and that participants have become more physically active which in turn resulted in an increase in aerobic endurance.

Compared to baseline, functional mobility (TUG) improved both half-way the intervention as well as at the six-months follow-up. However, during the second half of the intervention, a small decrease in functional mobility was found. This may be explained by the fact that during the first half of the intervention the content of the *VIPP*-program had a relatively strong focus on mobility-related topics, whereas in the second part of the intervention more time was spend on the other components of the program such as the individual and group goal-setting.

In the present study, aerobic endurance was measured with the 2-minute step test. Other studies, investigating the effectiveness of physical exercise programs, mostly used the 6-minute walking test [38]. This test, however, was not suitable for our study since the visually impaired participants would have needed help of an other person to lead them the track of the walking test. The presence of a coach would have influenced the test results which would have been a threat to the reliability and the validity of the test results. A previous pilot study on the suitability of performance based physical fitness tests for the visually impaired elderly [34] showed that the 2-minute step test is a good alternative to the 6-minute walking test, which is confirmed by other studies [26]. Other options such as the use of treadmills or ergometers were not possible not only because of the extra expenses, but also because of the limited feasibility. For our target population, i.e., the visually impaired elderly, the 2-minute step test appeared to be the most functional and cost-effective test.

The primary goal of the telephone coaching was to encourage participants to become or to stay physically active by stimulating them to follow the walking program and to perform physical exercises three times a week. The implementation of the walking program and the physical exercises, as well as the individual progress were discussed during the telephone conversations. The second goal of the telephone coaching was to increase the awareness of the benefits of being physically active and to discuss the potential barriers and difficulties that people may experience. Since aerobic endurance and functional mobility increased during the six-months follow-up period, we assume that participants stayed physically active after the completion of the *VIPP*-program. However, the results of a study on the impact of the *VIPP*-program on participation [30] did not show an increase in the frequency of performing physical activities as measured with the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) [39,40]. This may be explained by the fact that the reproducibility of the frequency subscale of the USER-P is suboptimal [40]. In addition to administering the USER-P, we asked participants to keep a diary in which they could record their physical activities. However, our pilot study showed that this was not feasible for our study population due to restrictions in reading and writing. Consequently, we were not able to assess the physical activities that were performed beyond the physical activities included in the *VIPP*-program.

The results of the present study are relevant since physical fitness not only has a positive influence on quality of life [41], but is also associated with participation [22-24]. A higher level of physical fitness is associated with more participation. The impact of the *VIPP*-program on participation is described by Alma et al. [30]. This study showed that the *VIPP*-program modestly benefits perceived restrictions in participation, satisfaction with participation and autonomy outdoors [30].

Despite the knowledge that regular physical activity is important for the visually impaired elderly, little attention has been paid to these topics within the rehabilitation process. There

is also little research in this area. To our knowledge, only one study focused on physical activity and physical fitness among the visually impaired population. Surakka and Kivela [42] described the effectiveness of a physical activity intervention for visually impaired people. This five-to-six-week program consists of three training sessions of 60 minutes a week and aims to improve balance, coordination and relaxation of the neck- and shoulder muscles. The majority of the participants perceived an increase in aerobic endurance and balance as well as an improvement in mental health [42].

To our knowledge, the present study is one of the first studies that investigated the impact of low-vision rehabilitation on physical fitness – measured as aerobic endurance and functional mobility – among the visually impaired elderly. As a consequence, there was no knowledge available on the methodology of measuring physical fitness among this population. Although the 2-minute step test and the Timed Up an Go test are reliable and valid tests for the normally sighted elderly [26], it is unknown whether these tests are reliable and valid for the visually impaired elderly population. Other limitations of this pilot study are the small sample size and the lack of a control group. Consequently, the results of the study should be interpreted with taking these limitations into account. Due to the multiple components of *VIPP*, we are not able to attribute the positive effects on aerobic endurance and functional mobility to one specific component of the program. However, we expect that the home-based exercise program with telephone coaching led to the improvement in aerobic endurance and functional mobility. Further research is needed to show if the home-based exercise program actually contributed to the positive effects found in this study. In addition, a study design that includes a control group is needed for a convincing estimation of the changes in physical fitness.

Although the findings are preliminary due to the study design, it is likely that the *VIPP*-program has a positive effect on aerobic endurance and functional mobility among the visually impaired elderly. Since a higher level of physical fitness is associated with more participation [22-24], this is a relevant result. It is important that the visually impaired elderly are offered to follow the *VIPP*-program, since research showed that the visually impaired elderly participate less compared to peers [15]. Currently, the *VIPP*-program is not available as part of the low-vision rehabilitation services and it will be a challenge to implement the program in the near future. Finally, physiotherapists should have a role in the process of implementation of *VIPP* and should be involved in running the home-based exercise component of the program.

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7.5 References

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8

The effectiveness of a multidisciplinary group rehabilitation program on psychosocial functioning of the visually impaired elderly

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ABSTRACT

The effectiveness of a multidisciplinary group rehabilitation program *Visually Impaired elderly Persons Participating (VIPP)* on psychosocial functioning was assessed in a single group pre-test post-test study. The findings indicate positive effects of the *VIPP*-program on adaptation to vision loss, helplessness, self-efficacy, mental health, and fear of falling.

8.1 Introduction

Decline in visual function is a common problem among the elderly population. The majority (79%) of the visually impaired persons in the Netherlands is aged 65 years and over [1]. Due to the aging of the population there will be a rise in the number of elderly persons with a visual impairment [2]. Along with the general consequences of aging, these elderly persons will experience restrictions in daily life due to vision loss. Impaired functional ability [3], difficulties in performing activities [4] and participation restrictions [5] may lead to dependency.

It is not surprising that vision loss requires substantial psychosocial adjustment, a process many visually impaired persons are struggling with [6]. The psychosocial impact is profound, evidenced by an elevated risk for depression [7], the high level of emotional distress [8], and reduced mental health [9] of visually impaired persons. Psychological problems, in turn, may further reduce social functioning and may lead to social isolation and loneliness [10]. Fear of falling, for example, is common among the visually impaired elderly [11] and leads to avoidance of activities [12] and consequently may act as a barrier for participation. Improvement of psychosocial functioning, therefore, should be an important goal of the rehabilitation of visually impaired persons [13].

In a previous study [14], we described the development of the multidisciplinary group rehabilitation program *Visually Impaired elderly Persons Participating (VIPP)*, which aims to enhance participation of the visually impaired elderly as well as to improve practical skills and physical fitness, and to promote adaptation to vision loss. In the present study we investigate the impact of *VIPP* on psychosocial functioning, i.e., adaptation to vision loss, helplessness, self-efficacy, mental health and fear of falling, as impaired psychosocial functioning may lead to participation restrictions.

8.2 Methods

8.2.1 Study participants

Study participants originated from a previous cross-sectional study [5] that included visually impaired persons who were aged ≥55 years, able to speak Dutch, able to understand instructions concerning response sets and referred to a low-vision rehabilitation center according to the Dutch guidelines [15]. Study participants were eligible for this pilot study if they were able to walk (with or without a walking aid) and if they had a total score ≤7 on outdoor participation, measured as going out to recreational, cultural and public places (response category: 0 [never] – 5 [once a week or more]; total score range: 0-15).

In November 2008, 134 visually impaired elderly persons received information about the *VIPP*-program by mail. Forty-three elderly (32%) were interested and received detailed

information about the *VIPP*-program by phone. Finally, 29 (22%) persons gave informed consent of which 26 (90%) completed the whole intervention program. Non-response analysis showed no significant differences between those who participated in the study and those who declined (n=87) with respect to age, gender, partner status, binocular visual acuity and pre-intervention levels of participation ($p>0.05$).

8.2.2 Design

This study had a single group pre-test post-test design. Data were collected by face-to-face interviews performed by experienced interviewers at baseline (pre-test, T0 – January 2009), after 12 weeks (halfway through the intervention, T1 – April 2009), immediately after the completion of the intervention (short-term post-test, T2 – June 2009), and six months after the intervention (long-term follow-up, T3 - December 2009). The study followed the tenets of the Declaration of Helsinki and was reviewed by the Medical Ethics Committee of the University Medical Center Groningen.

8.2.3 Development of the VIPP-PROGRAM

The multidisciplinary group rehabilitation program *VIPP was* developed according to the principles of intervention mapping [16]. For this purpose, we reviewed the literature, performed three focus group interviews (two with the target population of visually impaired elderly persons (n=8 and n=9) and one with delegates of interest groups for blind and visually impaired people (n=7)), organized an expert meeting with health professionals involved in low-vision rehabilitation, researchers and visually impaired persons (n=9), and examined determinants of participation [17]. The results guided the development and design of the *VIPP*-program. In consultation with the physical therapist, occupational therapists, and social workers of the low-vision rehabilitation center involved, a program manual was written. The program aims to promote adaptation to vision loss and to improve psychosocial functioning.

VIPP consists of 20 structured weekly group sessions (duration 2 hours) and a booster session 12 weeks after the completion of the program. The *VIPP*-program consists of four components: 1) training of practical skills, 2) education, social interaction, counseling and training of problem-solving skills; 3) individual and group goal-setting; and 4) a home-based exercise program. The structured sessions start with 60 minutes of practical training by two occupational therapists. After a 15-minute break, a social worker continues with a 45 minutes education and counseling session. Additionally, an exercise coach introduces simple physical exercises and a graded walking program and delivers counseling by means of 12 telephone conversations throughout the program according the principles of motivational interviewing [18]. The progress, benefits and difficulties of physical activity as perceived by the subjects are being discussed.

Sessions were conducted in small groups that contained sufficient participants to enable social interaction but had a maximum of nine participants to ensure safety within the practical training component. All supervisors of the program were trained before the start of the intervention. Detailed information of the program can be obtained with the first author (MAA).

8.2.4 Measures

To assess adaptation to vision loss, the Dutch version of the Adaptation to Age-Related Vision Loss Scale (N-AVL-12)[19] was used, which is a measure of psychosocial adjustment specifically developed for older adults who need to adapt to late-life vision loss. The Likert type scale ranged from 0 (strongly agree) to 3 (strongly disagree). Total scale scores ranged from 0 to 36, with higher scores indicating better adaptation (Cronbach's alphas (α) ranged from 0.70 to 0.80).

Helplessness refers to an attributional style explaining negative events and its consequences as uncontrollable, unpredictable and unchangeable, and was assessed with the 6-item subscale of the Illness Cognition Questionnaire (ICQ)[20]. Participants were asked to indicate the extent to which they agreed with the items on a 4-point Likert type scale ranging from 1 (not at all) to 4 (completely). Scale scores ranged from 6 to 24, with higher scores indicating more helplessness (α: 0.72-0.85).

Self-efficacy, assessed with a subscale of the Self-Management Ability Scale-30 (SMAS-30; version 1, 2004)[21] refers to the ability to gain and maintain a belief in personal competence [22]. The self-efficacy subscale consists of five items with a Likert type response category ranging from 1 (never) to 6 (very often). Scale scores ranged from 5 to 30, with higher scores indicating more self-efficacy (α: 0.61-0.80).

Mental health was assessed with the 5-item subscale of the RAND-36 [23]. This subscale assesses feelings of depression and nervousness on a 6-point Likert type scale from 1 (all of the time) to 6 (none of the time). According to the manual, raw scale scores were transformed to a 0-100 scale with a higher score indicating a better mental health (α: 0.69-0.82).

Two aspects of fear of falling were measured: generic and vision-specific fear of falling. Generic fear of falling assesses the level of fear of falling when performing easy and difficult physical and social activities. It was measured with the 16-item Falls-Efficacy Scale (FES)[24] on a 4-point scale (1 [not at all concerned] to 4 [very concerned]) with a scale score ranging from 16 to 64, with higher scores indicating more fear of falling (α: 0.87-0.93). Vision-specific fear of falling assesses the level of fear of falling when using public transport, crossing the street, walking up and down steps, walking in an area with many obstacles, walking in heavy traffic, and walking in a noisy area. These items were based on a study of Marquant [25] and measured similar as the method in the FES. The total vision-specific fear of falling scale

score ranged from 6 to 24, with higher scores indicating more vision-specific fear of falling (α: 0.85-0.92).

8.2.5 Statistical analysis

All analyses were performed using the statistical software package SPSS version 16.0. Non-response analysis was performed with Student's *t*-tests and Chi-square tests. Missing values were imputed according to the questionnaires or with the average score of the completed items in the scale, provided that at least 50% of the items were completed.

The effect of the *VIPP*-program on psychosocial outcome measures was tested with one-way repeated measures analyses of variance (ANOVA) and contrast tests (contrast repeated and contrast simple [reference first]). Level of statistical significance was set on 0.05.

In addition to statistical testing, effect sizes are reported, which is recommend particularly in the case of small sample sizes [26]. The eta squared (η^2) is a measure of the effect size for use in ANOVA and expresses the proportion of variance explained by the intervention. An eta squared of 0.01 is equal to 1% of explained variance and constitutes a small effect, 6% a medium effect, and 14% a large effect [27]. For the contrast tests, the effect size (r) was calculated by the square root of the F-statistic fraction of the contrast test divided by the sum of this F-statistic and the degrees of freedom of the residuals [28]. An ES (r) of 0.10 constitutes a small effect, 0.30 a medium effect and 0.50 a large effect [27].

8.3 Results

Twenty-nine visually impaired persons were included in this study. Three persons (10%) decided to withdraw after the first session (mean age 71.3 years, 33% female, mean visual acuity: 0.47logMAR). Because of the small number, we did not test for differences between those who completed the study and those who withdrew. Table 8.1 shows descriptive characteristics at baseline of the subjects who completed the *VIPP*-program.

Six subjects (23%) attended all 20 sessions of the *VIPP*-program. Three subjects (12%) missed one session, 15% (n=4) missed two sessions, 19% (n=5) missed three sessions, 15% (n=4) missed four sessions and four subjects (15%) missed five or more sessions. The exercise coach completed the twelve telephone conversations as planned with 50% of the subjects. Forty-six percent missed only one conversation, and one subject missed two conversations. Mean duration of the conversations was 14 minutes (SD 4.7; range 3-46). Reasons for missing a session or a telephone conversation were illness, holidays, interference with other appointments, or subjects could not be reached by phone.

Table 8.1: Descriptive characteristics of the study population at baseline (n = 26)

Characteristic	Value – n (%)[a]
Age, years	
Mean ± SD	73.2 ± 8.0
Range	57 – 88
Gender, female	18 (69)
Partner status, partner	12 (46)
Educational level[b]	
(Pre)Primary	5 (19)
Lower secondary	13 (50)
Upper secondary	6 (23)
Tertiary	2 (8)
Self-perceived vision (VFQ-25[c])	
Fair	6 (23)
Poor	11 (42)
Very poor	6 (23)
Completely blind	3 (12)
Binocular visual acuity (VODS)	
Median	0.20
Mean ± SD (logMAR[d])	0.88 ± 0.73
Duration of visual impairment, years	
Median	8.5
Range	3 – 59
Primary cause of visual impairment	
Age-related maculopathy	14 (54)
Vascular disorders[e]	2 (8)
Optic nerve disorders	1 (4)
Congenital and hereditary disorders[f]	1 (4)
Trauma	1 (4)
Cause unknown	3 (12)
Combination of causes	4 (15)
Co-morbidity	
0	4 (15)
1	14 (54)
≥2	8 (31)
Type of co-morbid conditions	
Diabetes mellitus	6 (23)
Osteoarthritis	7 (27)
Diseases of the respiratory system	2 (8)
Other chronic conditions[g]	17 (65)

[a] Percentages are based on totals for each category, and may not total 100 because of rounding
[b] International Standard Classification of Education (ISCED) [39]
[c] VFQ-25, Visual Functioning Questionnaire [40], general vision subscale: "At the present time, would you say your eyesight using both eyes (with glasses or contact lenses) is excellent, good, fair, poor, very poor or are you completely blind?"
[d] LogMAR value: –log visual acuity
[e] e.g. diabetic retinopathy
[f] e.g. retinitis pigmentosa
[g] e.g. diseases of the circulatory system, rheumatoid arthritis, diseases of the vestibular system, neurological disorders

Table 8.2 presents the mean scale scores of the psychosocial outcome measures at T0, T1, T2 and T3. To facilitate comparison between the different outcome measures and to visualize the changes throughout the intervention, we standardized the raw scale scores by transforming the raw scale scores to a 0 to 100 scale which are presented in Figure 8.1.

Table 8.2: Mean scores on the psychosocial outcome measures at pre-test (T0), half-way through the intervention (T1), short-term post-test (T2) and long-term follow-up (T3)

Outcome measure	T0 mean (SD)	T1 mean (SD)	T2 mean (SD)	T3 mean (SD)
Adaptation to vision loss (N-AVL-12)	21.4 (6.4)	24.3 (5.7)	25.1 (5.2)	23.9 (5.8)
Helplessness (ICQ)	15.2 (4.8)	14.1 (4.8)	14.2 (3.9)	13.1 (4.4)
Self-efficacy (SMAS-30)	20.3 (2.8)	21.2 (2.9)	21.9 (2.7)	19.9 (3.2)
Mental health (RAND-36)	68.2 (16.9)	70.2 (17.7)	75.7 (16.0)	72.5 (18.9)
Fear of falling				
Generic (FES)	26.8 (8.1)	26.5 (9.1)	25.8 (7.7)	28.2 (9.7)
Vision-specific	13.6 (5.0)	11.9 (4.8)	12.7 (4.8)	12.5 (5.3)

Note: Higher scores indicate better adaptation, more helplessness, more self-efficacy, better mental health and more fear of falling

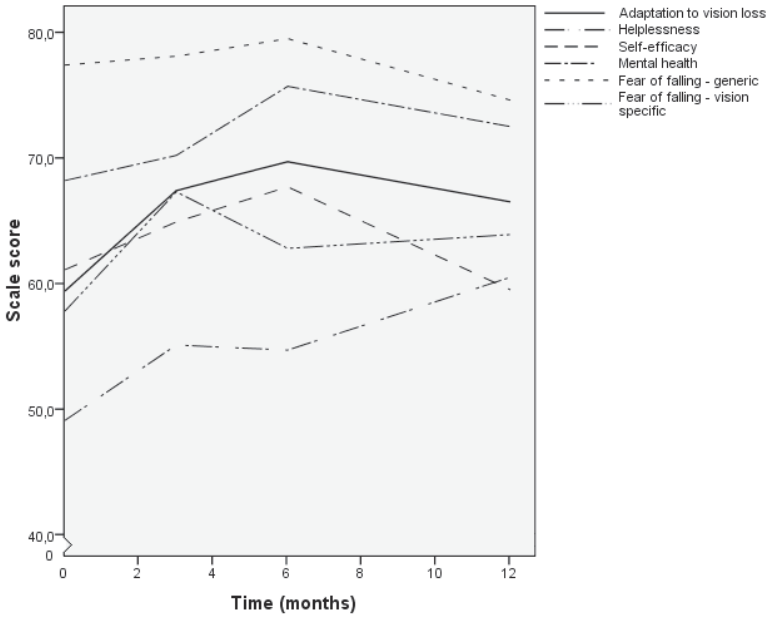

Figure 8.1: Changes in the outcome measures throughout the intervention with higher scores indicating better psychosocial functioning

Note: Higher scores indicate better adaptation, less helplessness, more self-efficacy, better mental health and less fear of falling

The one-way repeated measures ANOVA (Table 8.3) showed statistical significant differences for three out of the five psychosocial outcome measures. Large intervention effects were found for adaptation to vision loss (η^2=0.24; p<0.001) and self-efficacy (η^2=0.16; p=0.004) and a medium effect for helplessness (η^2=0.10; p=0.046). There were medium effects for mental health (η^2=0.07; p=0.15), generic fear of falling (η^2=0.06; p=0.22) and vision-specific fear of falling (η^2=0.07; p=0.13), although not statistically significant.

The level of adaptation to vision loss increased during the first part of the intervention (T0-T1: ES(r)=0.62) and further increased during the second part of *VIPP* (T1-T2: r=0.19). After the completion of the intervention, the level of adaptation decreased (T2-T3: r=0.27). Comparison between baseline and long-term follow-up indicated an overall improvement in adaptation to vision loss (T0-T3: r=0.54).

The results with regard to helplessness showed a decrease in helplessness during the first part of the intervention (r=0.25). After the completion of the intervention there was a further decrease of helplessness (r=0.33) which resulted in a decrease in helplessness at long-term follow-up compared to baseline (r=0.53).

With respect to self-efficacy, the *VIPP*-program initiated an increase in self-efficacy during the first part (r=0.30) as well as during the second part of the intervention (r=0.23). This effect, however, was not maintained after completion of the intervention, as shown by the decreased level in self-efficacy found at long-term follow-up (r=0.58). Self-efficacy at long-term follow-up was lower compared to baseline (r=0.14).

The effect sizes of mental health showed a pattern that was similar as was found for self-efficacy. Mental health improved during the intervention (r=0.11 and r=0.36, respectively), but decreased once the intervention was completed (r=0.27). Comparison between baseline and long-term follow-up, however, indicated an overall improvement in mental health (r=0.22).

With respect to fear of falling, we found a decrease in generic fear of falling during the second part of the intervention (r=0.17), but an increase after completion of the intervention (r=0.35). At long-term follow-up, generic fear of falling was higher compared to baseline (r=0.18). Considering vision-specific fear of falling, results showed a decrease during the first part of the intervention (r=0.50), but an increase in the second half of the *VIPP*-program (r=0.27). Comparison between baseline and long-term follow-up, however, indicated a decrease in vision-specific fear of falling (r=0.27).

Table 8.3: Comparison of the mean scores of the psychosocial outcome measures at pre-test (T0), halfway (T1), post-test (T2), and at six-months follow-up (T3)

Outcome measure	ANOVA		T0-T1		T1-T2		T2-T3		T0-T2		T0-T3	
	F^a	η^2	F^b	ES	F^b	ES	F^b	ES	F^b	ES	F^b	ES
Adaptation[c]	7.73***	0.24	15.33**	0.62	0.93	0.19	1.93	0.27	12.13**	0.57	10.41**	0.54
Helplessness	2.80*	0.10	1.60	0.25	0.01	0.02	2.96	0.33	1.80	0.26	9.68**	0.53
Self-efficacy	4.90**	0.16	2.41	0.30	1.36	0.23	12.68***	0.58	7.94***	0.50	0.51	0.14
Mental health	1.83	0.07	0.32	0.11	3.69	0.36	1.89	0.27	4.45*	0.39	1.22	0.22
Fear of falling												
Generic[d]	1.53	0.06	0.09	0.06	0.73	0.17	3.59	0.35	0.96	0.20	0.87	0.18
Vision-specific	1.95	0.07	8.27**	0.50	2.03	0.27	0.06	0.05	1.55	0.24	1.89	0.27

[a] Degrees of freedom of the F-statistic were (3,75)
[b] Degrees of freedom of the F-statistic were (1,25)
[c] Sphericity was not assumed; F-statistic was the average of Greenhouse-Geisser adjusted F-statistic (2.309, 57.720) and Huynh-Feldt F-statistic (2.557, 63.933)
[d] Sphericity was not assumed; F-statistic was the average of Greenhouse-Geisser adjusted F-statistic (2.316, 57.892) and Huynh-Feldt F-statistic (2.566, 64.149)
*p<0.05; **p<0.01; ***p<0.001

8.4 Discussion

The aim of this study was to investigate the impact of the *VIPP*-program on psychosocial functioning of the visually impaired elderly. Directly after completion of the intervention, we found an increase in adaptation to vision loss and self-efficacy as well as a better mental health compared to baseline. In addition, helplessness, and generic and vision-specific fear of falling decreased. The 6-months follow-up measure indicated improved adaptation to vision loss, less feelings of helplessness, a better mental health and less vision-specific fear of falling. In contrast, we found a decrease in self-efficacy and an increase in generic fear of falling at long-term follow-up compared to baseline.

With respect to the effect directly after the completion of the intervention, we found improved functioning for all outcome measures. Between the completion of the intervention and the 6-months follow-up measure, only helplessness further improved, whereas the effect of vision-specific fear of falling remained stable. The improvement in adaptation to vision loss and mental health during the intervention appeared to be a temporary effect and was followed by a decline after the intervention was completed. However, the 6-months follow-up measure still indicated a positive effect of *VIPP* compared to baseline. Unexpectedly, we found worse outcomes for self-efficacy and generic fear of falling at long-term follow-up. A possible seasonal effect may account for these negative outcomes, since the 6-months follow-up measure took place in December, whereas T2 took place in the summer. Regular additional booster sessions may be useful in preventing the decline in psychosocial functioning long-term after the intervention. Future studies have to show whether this decline is continued after six months or that it is only temporarily.

The psychological consequences of vision loss are increasingly recognized as an important component of the rehabilitation process and consequently have been investigated in previous studies. Our study results are in line with the studies of Packer et al. [29] and Girdler et al. [30] who reported positive effects of an 8-week vision self-management program on adaptation to vision loss and on mental health immediately following the program and at 12-weeks follow-up. A comprehensive in-patient rehabilitation training program for blind persons showed improved mental health immediately after rehabilitation and at 6-months follow-up [31]. Likewise, Brody et al. [32,33] found a reduction in depressive symptoms among depressed participants immediately and six months after a self-management program. As far as we know, no studies assessed the effects of low-vision rehabilitation on helplessness and fear of falling. However, in the Netherlands, there is a study in progress that will assess the effects of a standardized orientation and mobility training on fear of falling in older adults with low vision [34].

With respect to self-efficacy, our findings are not consistent with other studies that found positive effects for general self-efficacy [30] and disease specific self-efficacy [29,30,32,33],

whereas we only found a temporary effect during the intervention which had diminished at 6-months follow-up. This may be explained by the fact that we measured self-efficacy as a general self-management ability, defined as the ability to gain and maintain a belief in personal competence [22]. In contrast, Brody et al. [32,33], Packer et al. [29] and Girdler et al. [30] measured disease-specific self-efficacy with the Age-related Macular Degeneration Self-Efficacy Questionnaire (AMD-SEQ) or Age-Related Vision Loss Self-Efficacy Questionnaire (ARVL-SEQ), which evaluate the degree of self-confidence in the individual's ability to handle situations related to vision loss.

Our previous cross-sectional study showed that visually impaired elderly persons perceive restrictions in participation in society and are less involved in household, sports and recreational activities compared to peers [5]. As participation contributes to well-being it is important that visually impaired elderly persons maintain their level of participation during the process of vision loss. However, they have to face many barriers. The present intervention study focused on psychosocial functioning which may be regarded as a potential facilitator of participation [17].

The *VIPP*-program is as far as we know the first low-vision intervention that combines a multidisciplinary group intervention with an individual goal-setting component and a home-based exercise program. Group-based programs offer the opportunity for social interaction and allow participants to share experiences and coping strategies for both functional and emotional issues [6]. Contact with peers allows social support which seems to be an effective buffer against the negative effects of vision loss [35]. Besides the added value of group learning, the individual goal-setting component of the intervention enhances a person's motivation and assists visually impaired persons in their search for meaningful goals [36]. The multidisciplinary approach of the *VIPP*-program refers to the multidimensional learning process of the visually impaired as they have to acquire new skills and have to cope with the loss of normal vision in addition to the emotional shift from being a normally sighted person to being a visually impaired person [37]. However, due to these multiple components and the design of our study, we are not able to attribute the effects we found to one specific component of the *VIPP*-program.

Despite the strengths of the *VIPP*-program, several issues should be considered when interpreting the findings of this study. Although the small sample size limits the statistical power of the study, we found small to large effect-sizes. The pre-test post-test design, which has limited evidence compared to a randomized controlled design, complicates the interpretation of the findings. The absence of a control group makes it difficult to draw conclusions whether the effects we found were caused by the intervention or by other factors such as seasonal influences. Concerning the generalizability of our findings to the population of the visually impaired elderly, it should be noted that the present study included visually impaired elderly persons who were referred to and registered at a low-vision rehabilitation

center. This recruitment procedure may implicate selection of a subgroup of the visually impaired elderly, i.e., those who are motivated to seek rehabilitation. Lastly, the data on the outcome measures are self-report data derived through interviews which may implicate social desirability bias.

Vision loss causes major changes in life. Visually impaired persons are not able to perform activities of daily life as they were used to [3]. Changes in lifestyle, life habits and roles may result in problems with psychosocial adjustment [8]. The association between activity loss and psychological well-being indicates that low-vision rehabilitation programs should not only focus on practical skills related to vision loss but also on psychosocial aspects [38]. Therefore, the multidisciplinary group rehabilitation program *VIPP* included both. This pilot study is a first step towards documenting the effect of the *VIPP*-program on psychosocial functioning. Although the findings are preliminary because of the small sample size and the research design, the results are promising as shown by improved adaptation to vision loss, less feelings of helplessness, a better mental health and less vision-specific fear of falling at 6-months follow-up. Future studies among larger study populations are needed to offer further evidence of the results of this pilot study. Furthermore, an analysis of the costs of the *VIPP*-program relative to the benefits of the program should be made.

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9

General discussion

9.1 Introduction

Due to aging of the population the number of visually impaired elderly persons will strongly increase in the next decades [1,2]. Vision loss has a profound impact on daily functioning [3-5] and quality of life [6-9], as indicated by impaired functional ability and psychosocial problems [10-12]. With the ICF, the WHO introduced the concept of participation, which is defined as 'involvement in life situations' [13]. Since most previous research focused on clinical and functional aspects of vision loss [5,6,14-20], limited knowledge exists on the degree of participation of visually impaired persons. This thesis therefore had the following research questions:

1. To what extent do visually impaired elderly persons participate in society?
2. Which biological, social and psychological factors determine participation of visually impaired elderly persons?
3. What is the prevalence of loneliness among visually impaired elderly persons and what are the determinants of loneliness among visually impaired elderly persons?
4. What is the effect of the multidisciplinary group rehabilitation program on participation (i.e., primary outcome) and on physical and psychological functioning (i.e., the secondary outcomes)?

Two studies were performed to answer the research questions: a cross-sectional survey study addressed objectives 1 to 3, and an intervention pilot study addressed objective 4. The results of the survey study were used to develop a multidisciplinary group rehabilitation program, which was tested in an intervention study. In this final chapter the main findings of both studies are presented. Furthermore, the theoretical and methodological considerations will be discussed as well as the implications of our findings for low-vision rehabilitation and future research.

9.2 Main findings

9.2.1 Participation of the visually impaired elderly

The first research question addressed the description of the degree of self-reported performance of participation in the visually impaired elderly and a comparison with population-based reference data. The results of the cross-sectional study among 173 visually impaired elderly persons underscored the commonness of restrictions in participation. The prevalence of perceived participation restrictions varied from 54% in socializing (interpersonal interactions and relationships) to 84%, 86% and 92% for household activities (domestic life), leisure activities (community, social and civic life) and paid or voluntary work (major life areas), respectively. Despite these restrictions, we showed that visually impaired elderly persons do participate in society as the majority was engaged in household activities, in

shopping, in socializing with family, friends and neighbors, and in hobby activities. However, the visually impaired elderly participate less in society compared to peers. We showed that the visually impaired elderly study population was less engaged in household activities and sports activities and went less often to recreational places.

9.2.2 Determinants of participation

Knowledge of determinants is needed in order to influence the level and extent of an individual's participation and to implement intervention strategies to prevent participation restrictions and to enhance participation in society. It was shown that younger participants (i.e., <75 years) were more engaged in heavy household activities and hobby activities, and had more holidays compared to older participants. In line with these results, univariate analyses showed that age was associated with three out of four participation domains. However, multivariately, age was only associated with participation in domestic life. With respect to the physical health status, we found that vision-related variables (i.e., severity, duration, and primary cause) had no effect on participation whereas perceived physical fitness is a determinant of participation in domestic life. Of the social status factors, a larger social network size was associated with more participation in major life areas. The psychological status factors (i.e., mental health, helplessness, self-efficacy, and taking initiatives) contributed to the explained variance of participation across the domains. However, a significant association was only found for the domestic life domain: a higher level of helplessness was associated with decreased participation in this domain. According to our results, perceived importance, which refers to the value which an individual attaches to a certain participation domain, appeared to be a major determinant in three out of four participation domains (i.e., interpersonal interactions and relationships, major life areas, and community, social and civic life).

9.2.3 Loneliness: prevalence and determinants

The third research question addressed the prevalence of loneliness among visually impaired elderly persons and examined determinants of loneliness with a special focus on self-management abilities (SMAs). It was shown that the visually impaired elderly are at risk for loneliness since 50% of the visually impaired elderly experienced loneliness. Fourteen percent of them felt extremely lonely. In contrast, 29% of the normally sighted reference population experienced loneliness indicating that visually impaired elderly experience significantly more loneliness than the normally sighted elderly. With respect to determinants of loneliness, the results showed that the SMA self-efficacy was the strongest determinant of loneliness. In contrast, the SMA taking initiatives was not related to loneliness in a multivariate model, although analysis at the bivariate level indicated an association with loneliness. In addition, having a partner and higher levels of self-esteem were directly associated with less feelings of loneliness among the visually impaired elderly.

9.2.4 Effects of the intervention

Another purpose of the study was to develop a multidisciplinary group rehabilitation program which aims to enhance participation: the *Visually Impaired elderly Persons Participating* program (*VIPP*). With respect to the primary outcome of this study, i.e., participation, our single group pre-test post-test pilot study among 26 visually impaired elderly persons showed that the *VIPP*-program modestly benefits subjective aspects of participation. At scale-level, no statistically significant changes were found for the frequency of participation, whereas small effects were found for restrictions in and satisfaction with participation, and a medium effect for autonomy outdoors. At item level, the frequency of participation increased for some particular activities (i.e., unpaid work, housekeeping, leisure indoors) whereas participation in other activities did not change or decreased (i.e., paid work, physical exercise, chores in/around house). Furthermore, we found a decrease in restrictions in housekeeping and outdoor activities. Participants reported an increase in satisfaction with participation in leisure outdoors and indoors, and with the partner relationship. Lastly, the pilot study showed an increase in autonomy in using leisure time.

With respect to the secondary outcome measures, results of the pilot study showed that physical functioning increased, as indicated by an improved aerobic endurance and functional mobility. In addition, the results suggest that the *VIPP*-program has both short-term and long-term benefits on psychosocial functioning. In the short-term, we found an increase in adaptation to vision loss, self-efficacy and mental health whereas helplessness and vision specific fear of falling decreased. In the long-term, adaptation to vision loss and mental health increased, whereas helplessness and vision specific fear of falling decreased. In contrast, a decrease in self-efficacy and an increase in generic fear of falling were found in the long-term.

9.3 Theoretical considerations

9.3.1 Participation

The central theme of this thesis is participation which has become an important outcome measure of disease since it has been introduced by the World Health Organization in their International Classification of Functioning, Disability and Health [13]. Despite the acceptance and utilization of the ICF-model over the last decade, a number of issues and concerns have been raised. First, although the ICF depicts 'Activities' and 'Participation' separately in the model, it presents a single list with nine chapters covering both. There is some discussion about which chapters conceptually should be placed under the component of 'Participation' [21]. Some chapters clearly represent 'Activities', which is defined as the execution of specific tasks or actions, while other chapters clearly represent 'Participation' defined as involvement in life situations. In this thesis, we followed one of the options given by the ICF to differentiate 'Participation' from 'Activities', and identified four chapters that

represent participation (i.e., domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life). Whether domestic life is a domain of participation, or whether it is merely connected to activities is debatable. Whiteneck and Dijkers [22] recently stated that this chapter is the most difficult to allocate to 'Activities' versus 'Participation'. We classified this chapter of domestic life as 'Participation' since it relates to a social role and social interaction. This is also in line with a study of Jette et al. [23]. However, Whiteneck and Dijkers [22] concluded that the domestic life chapter mainly focuses on individual activities, except for the ICF code 'Assisting others', and therefore should be classified as 'Activities'. This discussion indicates that the distinction between 'Activities' and 'Participation' need to be clarified in the next revision of the ICF. For example by differentiating on complexity of activities.

Secondly, the ICF offers a comprehensive model of disability outcome, but does not address subjective dimensions of participation, such as satisfaction. By focusing on performance of particular activities or roles only, the meaning that a particular aspect of participation has for the individual is obscured and the concept's utility as an outcome measure is rendered meaningless [24]. The focus on performance has also been criticized for overlooking the influence of free will; what people do is not necessarily what they wish or choose to do [25-27]. Participation not only includes active engagement in life situations at the societal level, but it also includes the personal meaning and satisfaction resulting from that engagement [28]. As a result, the focus on performance of participation does not adequately capture the full meaning of participation [27]. Moreover, from the individual perspective it is important to know how the degree of participation is valued [24,28-31]. As was shown in previous studies objective (i.e., performance) and subjective participation (e.g., restrictions, satisfaction) represent two different concepts [32,33]. This distinction was confirmed by the results of the pilot intervention study. The *VIPP*-program appeared to benefit the subjective aspects of participation whereas no effect was found on the performance (frequency) of participation. Therefore, it is important to keep measures of participation performance distinct from measures of subjective participation [34].

Since previous studies showed that objective and subjective participation represent different concepts, it will be important to determine whether objective or subjective participation are more strongly related to measures of other subjective dimensions related to disability outcomes, such as well-being and quality of life (QoL) [35]. These concepts (i.e., well-being and QoL) are currently not part of the ICF. Researchers recommend augmenting the ICF with an additional dimension, i.e., QoL [36], which is defined as 'the perception of individuals of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns' [37]. QoL might be acknowledged by the ICF in several ways of which adding QoL as a separate domain to the right of participation, indicating that the extent of QoL is the ultimate outcome of the

disability process, is the most favorable [36,38]. If QoL is incorporated in the ICF, it will be critical that QoL be conceptually distinct from all other constructs in the ICF to avoid further confusion [22].

9.3.2 Participation of the visually impaired elderly

Studies with respect to self-reported performance of participation among the visually impaired elderly are scarce. To our knowledge, only Crews and Campbell [15] assessed participation of American visually impaired persons. In line with our findings, they showed that the majority is involved in socializing with relatives and friends. Although 54% of the visually impaired elderly perceived restrictions in socializing, we did not find any differences for the interpersonal interactions and relationships domain of participation between the visually impaired elderly study population and the reference population. Socializing was defined as meeting others in person including contact by telephone and e-mail. Since socializing does not necessarily require elderly persons to go outdoors, restrictions in outdoor mobility, which are prevalent in the visually impaired elderly [4], may be of less influence on this domain of participation. This seems in accordance with Wang and Boerner [39] who showed that the ways in which visually impaired persons relate to others change after vision loss. Visually impaired persons face challenges in relating to other people indicated by re-establishment or substitution of ways of communication [39,40]. Although our study showed no differences in the frequency of socializing, the visually impaired elderly do experience difficulties in socializing.

Although the survey study showed high prevalence rates of participation restrictions and that the visually impaired elderly participate less in society compared to peers and that those with a relatively poorer vision perceive more participation restrictions than those with a relatively better vision, it is remarkable that no effect was found for the vision-related characteristics in the univariate and multivariate models. The severity, duration and primary cause of the visual impairment, and self-perceived vision had no effect on participation. However, in line with our study, several studies have shown that the visually impaired elderly do perceive restrictions in participation [4,14,39-41]. Therefore, our results suggest that merely having a visual impairment leads to a reduced level of participation, whereas its severity apparently does not play any significant role within a sample of visually impaired elderly persons.

Despite the comprehensive biopsychosocial research model used in this thesis, only a part of the variance in participation could be explained. The explained variance ranged from 14.5% for interpersonal interactions and relationships to 28.2% for community, social and civic life. This may be explained by the fact that participation has multiple determinants which makes it difficult to explain participation more accurately [42]. Factors not included in our study may have had an impact on participation such as urban environmental factors.

As emphasized by Nagi [43] 'characteristics of the environment and the degree to which is it free from, or encumbered with, physical and sociocultural barriers' can lead to very different patterns and levels of participation in those with identical types of impairments. A recent study by Clarke et al. [44] showed that the level of participation among people with visual impairments varies by characteristics in the built environment such as poor street conditions, heavy traffic and low residential safety. These and other environmental factors such as the availability of (public) transport, accessibility of (public) buildings, the weather and noise may have constituted barriers for participation and could therefore add to the explained variance of participation. Current disability paradigms such as the ICF emphasize the interaction between the person and the environment. Not only the person and his or her characteristics are important, but also the environment in which the person lives, which determines the level of participation.

9.3.3 Loneliness

Social activities and social relationships with family, friends and neighbors are important to prevent feelings of loneliness [45-47], which is defined as an unpleasant feeling encompassing a lack of (quality of) certain relationships [48]. In the survey study, a prevalence of loneliness of 50% was found, which is in line with another Dutch study that reports a prevalence of 54% in the visually impaired elderly aged 55 years and over [49]. The significantly lower rate of loneliness (29%) in the reference population justifies the conclusion that the visually impaired elderly experience more feelings of loneliness than the normally sighted elderly.

With respect to determinants of loneliness, we were particularly interested in the effect of SMAs on loneliness. According to the Self-Management Well-being Theory (SMWT), SMAs are internal resources which refer to behavioral and cognitive abilities that people use to manage their external resources such as friends and social support, in order to achieve well-being [50]. SMAs can be regarded as skills which are necessary to obtain these external resources such as social relationships and social support which may protect the elderly against feelings of loneliness. In the survey study, we focused on two specific SMAs: self-efficacy and taking initiatives. In line with studies among the normally sighed elderly [51,52], the results showed that having more self-efficacy protects against feelings of loneliness. In contrast, the SMA taking initiatives was not related to loneliness. Although both SMAs are closely related, they are considered as separate abilities. The belief in one's competence is not automatically linked to the motivation to use one's competence. The results of the survey study indicate that the belief in one's competence or control is more important in proactively coping with feelings of loneliness than is the motivation to use this competence. However, this does not mean that taking initiatives is an insignificant ability. According to the SMWT, SMAs reinforce each other and cumulate to higher levels of self-management [50].

9.3.4 Visually Impaired elderly Persons Participating program (VIPP)

The main aim of the *VIPP*-program is to enhance the level of participation in society. At scale level, the pilot study had no statistically significant effect on the frequency of participation. Since engagement in participation is highly nuanced, personalized and customized to each individual's needs, preferences, social world, and available resources [28], it is important to focus on subjective aspects of participation as well. There is no standard for the ideal or optimal level of participation. Accordingly, there is not a defined set of activities or frequency of engagement that accounts for 'full' participation. People with disabilities viewed participation as an expression of their values rather than as a defined set of activities; it includes the personal meaning and satisfaction resulting from that engagement [28]. Therefore, the improvements in participation restrictions, satisfaction and autonomy after attending the VIPP-program are more relevant than changes in participation performance per se.

As stated before, we designated four ICF-chapters representing participation: (1) domestic life; (2) interpersonal interactions and relationships; (3) major life areas; and (4) community, social and civic life. The results of the pilot intervention study showed that the *VIPP*-program particularly benefits the domestic life domain of participation and the community, social and civic life domain, as indicated by the effects on housekeeping, outdoor and indoor leisure time activities. This is important since the survey study showed that the visually impaired elderly are less involved in household activities and went less often to recreational places compared to normally sighted peers. With respect to the interpersonal interactions and relationships domain of participation, participants indicated perceiving less restrictions and having an increased autonomy with regard to visiting family and friends. These results indicate that participation changed particularly in activities requiring going outdoors. This may suggest that the visually impaired elderly who attended the *VIPP*-program may perceive less outdoor mobility restrictions which is important since outdoor mobility restrictions are prevalent in visually impaired elderly persons [4].

A novelty of the *VIPP*-program is the inclusion of a physical exercise component. It is remarkable that in the literature there is little interest for the physical activity of visually impaired persons, whereas the health benefits of being physically active are generally recognized [53-57]. Moreover, several physical activity programs have been developed for the elderly population in the last decades [58-63]. Being physically active may be even more important for the visually impaired elderly population since baseline aerobic endurance levels of the *VIPP*-participants were significantly lower than those of a reference population of the elderly [64]. In addition, a recent study among patients with age-related macular degeneration showed that vision loss is related to musculoskeletal problems [65]. Furthermore, it is shown that older adults with vision loss are more often physically inactive than older adults without vision loss [66]. However, both visually impaired people and

rehabilitation professionals become increasingly aware of the importance of feeling fit as was shown in a focus group study on the development of the Dutch Activity Inventory (D-AI), an ICF-based instrument to investigate visual rehabilitation needs of visually impaired older adults [67]. To our knowledge, only one study described the effects of an exercise intervention that aimed to develop balance and coordination, and to relax the neck and shoulder muscles [68]. Results of this study showed that the majority of the participants perceived an increase in physical condition and balance after attending the physical training program [68].

Although, an increase in aerobic endurance and mobility was reported, we did not find an increase in the frequency of physical exercise as measured by the USER-P which defines physical exercise as sports activities and other forms of physical exercise such as playing tennis, cycling, fitness and walking. During the six-month follow-up, even a small decrease in the frequency of physical exercise was reported. There may be three explanations for the fact that an increase in aerobic endurance was reported, whereas no effect was reported for the frequency of physical exercise. First, at baseline, the majority (65%) scored the highest possible frequency (19 times or more in a week) on the physical exercise item of the USER-P, indicating a possible ceiling effect of this item. Consequently, they were not able to improve their score on this item due to these high baseline scores. However, it might be possible that the frequency of performing physical exercise increased and consequently increased their aerobic endurance and mobility. Secondly, it may be possible that improved aerobic endurance is a result of the increased frequency of performance of household activities, outdoor activities or leisure indoor activities. These activities also require exertion of the physiological system. And thirdly, although the frequency of physical exercise remained stable, it may be possible that the duration and the intensity of these activities increased which in turn may have led to improved aerobic endurance and mobility.

9.4 Methodological considerations

9.4.1 Study design

In the survey study, we were interested in the prevalence of participation and loneliness and in physical, social and psychological determinants of participation and loneliness. Since we studied the relationships between these variables cross-sectional, we cannot definitely assess causal relationships between the variables measured. Cross-sectional data do not provide information on causal relationships between variables, but merely describes associations. Longitudinal research is needed to determine the causal dynamics in adaptation to vision loss as well as to confirm the effects of physical, social and psychological status, and perceived importance on participation, and the effects of SMAs on loneliness.

The multidisciplinary group rehabilitation intervention *VIPP* was tested in a pre-test post-test design, which complicates the interpretation of the findings. The lack of a control group makes it difficult to draw conclusions whether the modest effects on participation and physical and psychosocial functioning were caused by the *VIPP*-program or by other factors such as seasonal influences. For a convincing estimation of the change in participation, and physical and psychosocial functioning, a randomized controlled trial is preferable. If feasible, future randomized controlled trials should include a usual care or waiting list control group. Including a placebo or no treatment group is not possible as it would be unethical to withhold patients from low-vision rehabilitation. Furthermore, the multiple dimensions of low-vision rehabilitation targeted in *VIPP* that were aggregated into an integrated program make it hard to detect exactly which aspects of *VIPP* contributed to the outcomes. The several elements could have contributed to the effects separately or in interaction. Moreover, it is possible that different visually impaired elderly persons benefited from different elements of *VIPP*. The data collected in the intervention study only allows restricted conclusions about what makes *VIPP* work.

9.4.2 Sample characteristics

Concerning the generalizability of our findings to the Dutch population of the visually impaired elderly, it should be noted that both the survey study as well as the intervention study included visually impaired elderly persons who were referred to and registered at a low-vision rehabilitation center. This recruitment procedure may implicate selection of a subgroup of the visually impaired elderly who are motivated to seek rehabilitation.

We had assumed that all the elderly persons visiting low-vision rehabilitation centers who formed our study population had severe visual impairment, but it appeared that some of them had a relatively good visual acuity. This may be a consequence of the Dutch Guidelines on the referral of visually impaired persons to low-vision services' [69]. According to these evidence-based guidelines, not only persons with a visual acuity <0.3 in the better eye should be referred for rehabilitation, but also persons with a visual field <30° as well as persons with a visual acuity <0.5 experiencing problems with reading or other daily life activities. Despite this relatively good visual acuity, they probably had enough problems in daily living to register at the rehabilitation center. This phenomenon is confirmed by several other studies [70-73].

In the survey study, the study participants and responders differed significantly with respect to age, indicating that non-responders were older. This fact and the response rate of 66% may have resulted in a response bias. Furthermore, this may have resulted in an overestimation of participation, because younger study participants had higher levels of participation. In addition, it is likely that non-responders were less willing to participate in the study, because they in general are less active. Study participants may therefore have been a select group of relatively active visually impaired elderly persons.

In order to compare the degree of participation and loneliness with normally sighted elderly, we used data of reference populations. The use of data from existing databases of population surveys to create a reference population is a highly efficient method. On the other hand, it also imposes restrictions on the data collection in the study to be performed.

9.4.3 Outcome measures

Since the development of the ICF, the measurement of participation became an important and much debated issue. The need for a measurement scale capturing participation resulted in the development of a variety of instruments [32,74-81]. Although participation is considered to be an important concept, there is no consensus yet on how participation should be measured [82], which is reflected by the diversity of the developed measurement scales. At the time of the data collection, based on a review of Perenboom and Chorus [83] and our own literature search, we concluded that no participation questionnaire was available that met our requirements of assessing performance of participation in the four ICF-domains, and facilitated comparison with reference populations as well. In absence of an appropriate instrument for measuring participation at the time of the survey study, data on participation were collected by means of subsets of items extracted from available population surveys, which in itself is not equivalent to a validated questionnaire. Although some pilot interviews were performed, this subset of items was not tested on reliability and validity. In the time between the survey study and the intervention study, a new participation measure was developed: the Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P) [84]. Since this scale assessed both objective (i.e., frequency) and subjective (i.e., restrictions and satisfaction) aspects of participation in the four ICF-chapters we distinguished as participation, we decided to use this reliable and validated scale in the intervention study in addition to the subset of items extracted from available population surveys. However, considerable psychometric evaluation of existing and newly developed instruments is needed to reach a consensus on standardized methods of quantifying participation.

Except for physical functioning, all data on the primary and secondary outcome measures (i.e., participation, loneliness, psychosocial functioning) and determinants were self-reported derived through telephone and face-to-face interviews. Self-reporting is susceptible to social desirability bias; participants may report a higher level of participation, less loneliness and higher psychosocial functioning, feeling that higher levels are expected from them. In our studies, social desirability could have led to an overestimation of the level of participation and an overestimation of the effect of the *VIPP*-program.

To our knowledge, no studies have assessed physical functioning of the visually impaired elderly by performance-based measures of physical fitness. Since many performance-based measures of physical fitness are not suitable for visually impaired persons, we performed

a pilot study [85] in which different physical fitness tests were tested on suitability for the visually impaired elderly population. Based on this pilot study, we preferred using the 2-minute step test instead of the widely used 6-minute walking test since the majority of the visually impaired elderly population would need a guide who leads the way of the walking track. Although both the 2-minute step test and the Timed Up and Go (TUG) have shown good reliability and validity among the general elderly population [86], we do not know if these tests are reliable and valid for the visually impaired elderly.

9.4.4 Intervention

The reciprocal relationship between activity loss and psychological adjustment indicates that low-vision rehabilitation programs have the potential to be more powerful if they not only focus on practical skills but also on psychosocial aspects of vision loss [87,88]. Visually impaired persons have to acquire new skills and have to change their behavior patterns in addition to grieving the loss of normal vision and the emotional shift from being a normally sighted elderly to being a visually impaired person [89]. Therefore, the *Visually Impaired elderly Persons Participating* program *(VIPP)* has a multidisciplinary approach, including training of practical skills as well as education, counseling and training of problem-solving skills. A physical exercise component was included to improve physical fitness. Improving physical fitness is not only important since it is related with various positive health outcomes [53-57], but also since this survey study showed that physical fitness is associated with participation.

This *VIPP*-program has several additional strengths. Firstly, *VIPP* is a group-based program. Peer support groups provide the opportunity to share experiences and coping strategies on functional, social and emotional issues [90] providing a level of support that may not be present from other sources of support [91]. Another important advantage of the group method is the modeling aspect, as the participants serve as models for each other [92]. Secondly, besides the added value of group learning, the *VIPP*-program incorporated an individual component. *VIPP* actively assists participants in the search for and the re-engagement in new personal goals since vision loss causes goal impediments [93,94]. Individual goal-setting enhances a person's motivation and is a useful strategy for actively assisting visually impaired persons in their search for meaningful goals [90,94,95]. Commitment to personal goals and striving for the attainment of these goals is generally believed to be of great importance for psychological well-being [96,97].

Because of the multidisciplinary structure, the *VIPP*-program has a relatively long duration (20 weeks) in comparison with other low-vision rehabilitation interventions. It is recommended that low-vision rehabilitation interventions should be as short as possible because of the problems visually impaired persons have with transportation [98]. Our study, however, showed that only 7% of those interested in the *VIPP*-program declined to

participate because of this reason. Furthermore, the low drop-out rate (10%) indicates that the duration of the *VIPP*-program was not a barrier for attending the program although the percentage of non-attendance was substantial. It is likely that interventions with a relatively long duration more often are confronted with non-attendance, for example due to illness or participants holidays, hospital visits etc. The *VIPP* study participants expressed that they had no problem with the long duration as assessed in an evaluation session. A drawback of rehabilitation programs with a long duration is the additional costs.

9.5 Implications

9.5.1 Low-vision rehabilitation

Based on the positive results of the pilot intervention study with respect to the primary (i.e., participation) and secondary outcomes (i.e., physical and psychosocial functioning), one could advise to implement *VIPP* as a regular product of low-vision rehabilitation services. We also evaluated the program with the participants as well as with the supervisors of the program. Based on the results of the pilot study and these evaluation sessions, some recommendations can be made for further implementation of the program in low-vision rehabilitation.

Target population

The *VIPP*-program is intended for visually impaired persons aged 55 years and over. The youngest person participating in the pilot study was 57 and the oldest 88, indicating a wide range in ages among the participants. Although the participants themselves did not indicate this as a problem, the supervisors suggested reducing this age range because of large differences in physical functioning and stage of life between the participants. Since retirement in the Netherlands currently starts at the age of 65, one could argue to raise the lower age bound to 65. In that case, all participants are in the same stage of life, namely retirement. However, the *VIPP*-program could also be interesting for visually impaired people from younger age groups. The topics within the four components of *VIPP* should then be adjusted to topics relating to the problems younger visually impaired persons perceive.

For the pilot study, participants of the survey study who had a low level of participation were invited to follow the *VIPP*-program. In a normal rehabilitation trajectory, first an interview on admission to the low-vision rehabilitation center takes place when a patient makes himself or herself known at a low-vision rehabilitation center. In this interview, the problems perceived in daily life and the request for help is clarified. For some patients their request is quite clear (e.g., they need a closed circuit television (CCTV) or they need an identification cane), but for others their request is not clear. This latter group, who perceive problems in daily life due to the visual impairment but do not yet know what kind of help

they need, may be interested in following the *VIPP*-program. For future implementation of the program, those who register a patient at a low-vision rehabilitation center should explicitly offer the possibility of following the *VIPP*-program to that latter group of patients.

Group composition

In the pilot study, the group size varied from 4 to 9 participants. Supervisors indicated that a group of 4 persons was too small, especially in the case when someone did not attend a session. A group size of five to ten participants has been suggested as a size that would permit interaction among the participants [99] and no more than six to eight participants is recommended when working with the elderly [100]. Furthermore, it is important that varying degrees of visual acuity should be represented in the group. The differences allow them to learn from each another, and they serve as a role model for each other by making them aware of what their future might entail [92]. For practical reasons with respect to the practical training component of *VIPP*, a smaller group size (five or six) is suggested when including a completely blind participant in the group.

Frequency, duration and content of VIPP

The pilot program showed that many sessions could not start in time due to the fact that participants arrived lately because of the transport facilities. Therefore, the occupational therapists had often a shortage of time to perform all exercises according to the program manual. In addition, social workers indicated that 45 minutes were too short for their education, social interaction and training of problem-solving skills session. Therefore, it is recommended to extend the duration of the sessions to 2.5 hours of which the first 90 minutes are dedicated to practical training followed by one hour of education and counseling which starts with drinking coffee or tea.

Furthermore, the pilot program showed that not all topics within the practical training component were important to the participants (e.g., orientation and mobility in home). Each counseling and training of problem-solving skills session was followed by a session in which experiences on the topic of the previous training session were shared. Social workers indicated that these sessions were less useful since the topic was already discussed sufficiently during the training session according to the opinion of the participants. Although the participants expressed that they had no problem with the relatively long duration of *VIPP*, based on the remarks of the occupational therapists and social workers the *VIPP* program could be shortened to 12 sessions of 2.5 hours. This will also reduce the costs.

The results of the pilot study indicate that psychosocial functioning deteriorates during the six-month follow-up. This may reflect the need for additional booster sessions. The current policy of low-vision rehabilitation centers is to deliver 'patient-centered' care, which means that rehabilitation is offered to patients when they ask for it themselves and is not

driven by the availability of care or rehabilitation. Admission to low-vision rehabilitation services is limited by regulations imposed by the Dutch government that hamper long-term follow-up care. In practice, patients are no longer monitored after rehabilitation. However, based on the results we recommend adding extra booster sessions to the program. At least, *VIPP* instructors should emphasize that patients have the possibility to return to the low-vision rehabilitation center if their problem worsens, or if a new need for rehabilitation arises.

Individual goals

The pilot study showed that the participants had difficulties with setting their individual goals. The newly developed Dutch version of ICF Activity Inventory (D-AI) [67,101] might be a useful tool to help participants setting their goal. The D-AI is an instrument that systematically investigates the visual rehabilitation needs of visually impaired older adults. The D-AI rates the importance of goals on a scale of 0 (not important) to 3 (very important). If a goal is important, the difficulty of this goal will be rated on a scale of 0 (not difficult) to 4 (impossible). The responses can be used to prioritize rehabilitation goals by multiplying importance and difficulty scores to calculate a priority score. Since a pilot study on the feasibility of the D-AI showed that the mean administration time of the D-AI was 88.8 (±41.0) minutes [101], it is not possible to administer the D-AI in one group session. Therefore, we would recommend adding an individual introductory talk in which the D-AI is administered by one of the supervisors and in which the goal and content of the *VIPP*-program can be explained. When all individual goals are clear, the action plans can be made during a group session. Feedback from other group members can help the participant to adjust their action plan. In addition to an individual introductory talk, we recommend to add an individual closing talk as well in which the progress with respect to the individual goal can be evaluated and additional rehabilitation requests can be determined.

Realization home-based exercise program

As stated before, being physically active is relevant for the visually impaired elderly in order to improve physical fitness. Since for the pilot study an extra grant was available of which we could appoint an exercise coach, one of the main questions is how the 'home-based exercise program' component of *VIPP* should be implemented in the daily practice of current low-vision rehabilitation. There are several options to implement physical activity programs for the visually impaired elderly population.

First, low-vision rehabilitation centers should appoint physical therapists who will perform the telephone coaching according to the program manual or who could give physical exercise classes to all visually impaired clients of the low-vision rehabilitation center. It is advisable that these physical therapists receive an additional training in treating

visually impaired people. The Exceptional Medical Expenses Act (AWBZ) or health insurance companies should become aware of the interest of paying more attention to physical activity and should consequently finance these activities of low-vision rehabilitation services. Another option of stimulating the visually impaired elderly becoming more physically active is written information which is easy to apply and cheap. And visually impaired persons can re-read it when they feel like it. Low-vision rehabilitation centers could handle out a booklet in which the benefits of physical activity are explained and which gives examples of several physical exercises which are easy and safe to perform. Although studies on the effectiveness of written patient education showed conflicting results and patient-tailored education is probably more helpful toward achieving changes in physical activity, a booklet could be a first step in awakening to the benefits of being physically active.

Secondly, local authorities, provincial sports commissions and organizations like the Netherlands Institute for Sport and Physical Activity (NISB) should become aware of the fact that the number of visually impaired elderly persons will increase in the future. In the last decades, they developed and implemented several physical activity programs like Groningen Active Living Model (GALM), Sportive Walking, In Balance, and More Exercise for Seniors (MBVO). However, these existing programs are not suitable for the visually impaired elderly population and need, therefore, adaptation to the specific needs and restrictions connected with vision loss. Low-vision rehabilitation centers should cooperate with them in order to make these programs suitable for the visually impaired elderly population. Additionally, they should offer train-the-trainers courses in order to teach the special needs of the visually impaired elderly to the instructors of these programs.

Lastly, the internet is more and more used as a mode of delivery for physical activity programs since the number of people having access to and using the internet rapidly increases [102]. Internet based physical activity programs have some advantages: large numbers of individuals can be reached at lower costs [103], participants can access large amounts of information and they can choose the time when they would like to interact and receive information [104]. Therefore, health providers have started to disseminate behavioral interventions through the internet targeting physical activity information to the different stages of change (goal setting, activity planning, self-monitoring, rewards, using cues) (e.g., [105]). These interventions provide participants with personal relevant feedback produced by a computerized expert system and have induced changes in physical activity [105-108]. By using magnification- or speech recognition programs e-health interventions are feasible for the visually impaired population. In addition, e-health may be a useful tool to implement the home-based exercise program component in a way that could reduce costs.

9.5.2 Future research

The current study not only provided important data on participation and on the effect of the multidisciplinary group rehabilitation program *VIPP*, but generated several ideas for future research. First, we could only explain a part of the variance in participation. We suggested that other factors, i.e., (urban) environmental factors, may have had an impact on participation. Future studies have to show if these environmental factors could add to the explained variance of participation in addition to the biological, social and psychological factors.

For a convincing estimation of the change in participation, and physical and psychosocial functioning after the *VIPP*-program, a randomized controlled trial is preferable. Future randomized controlled trials on the effectiveness of *VIPP* should include a usual care or waiting list control group, since including a placebo or no treatment group is not possible as it would be unethical to withhold patients from low-vision rehabilitation. Furthermore, the question of whether participants need the whole package of the *VIPP*-program or could achieve the same improvement with only parts or combination of parts of the program remains unanswered. This should be studied in a randomized design and would improve understanding of what makes *VIPP* work. Lastly, an analysis of the costs of *VIPP* relative to the benefits would provide further evidence of its efficiency.

Finally, this thesis added to the knowledge on the participation of the visually impaired elderly, but more studies are needed to answer the remaining questions. Therefore, we would like to emphasize the importance of the InSight's research program of the Netherlands Organisation for Health Research and Development (ZonMW). This program aims to close the gap between scientific research and the applicability of results into care and rehabilitation of visually impaired people by funding scientific research aimed at enhancing social participation of people with a visual impairment.

9.6 Final conclusions

This thesis highlighted that the visually impaired elderly do participate in society, but that in some specific domains they participate less than their peers. In addition, participation restrictions are prevalent in the visually impaired elderly. Furthermore, the visually impaired elderly are burdened by the unpleasant feeling of loneliness. The results of this thesis add new insights into the determinants of participation and loneliness. Across the participation domains, perceived importance is a major determinant of participation. Physical health, along with social and psychological status, also affects participation. Furthermore, the results suggest that self-management training may be effective in reducing feelings of loneliness. This knowledge on determinants has been used to develop the multidisciplinary group rehabilitation program *VIPP* which aims to enhance participation by improving practical

skills, promoting adaptation to vision loss, and improving physical fitness. This thesis showed promising results with respect to the effectiveness of *VIPP*. The results indicated that the *VIPP*-program modestly benefits the perceived restrictions in participation, satisfaction with participation and autonomy outdoors. Additionally, increases in physical and psychosocial functioning were reported. Future studies have to endorse the results of the pilot study presented in this thesis.

9.7 References

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Summary

In the Netherlands, 79% of the visually impaired persons are aged 65 years and over. Due to aging of the population the number of visually impaired persons will increase. Vision loss has a profound impact on daily functioning and poses a severe threat to the independence of visually impaired persons. Previous studies among the visually impaired elderly mostly focused on clinical and functional outcome measures. Limited knowledge exists on social outcomes of vision loss such as participation in daily life. The concept of participation was introduced by the World Health Organization (WHO; 2001) in the International Classification of Functioning, Disability, and Health (ICF), and is defined as "involvement in life situations". Knowledge about participation is important, not only from the individual perspective but from the societal perspective as well: it gives an impression to what extent people are integrated in society. The main purpose of the study described in this thesis is: (1) to get insight in the degree of participation of visually impaired elderly persons and to identify determinants of this participation; and (2) to develop and test a multidisciplinary group rehabilitation program which aims to enhance the level of participation of the visually impaired elderly. These aims resulted in the following research questions that will be addressed in this thesis:

1. To what extent do visually impaired elderly persons participate in society?
2. Which biological, social and psychological factors determine participation of visually impaired elderly persons?
3. What is the prevalence of loneliness among visually impaired elderly persons and what are the determinants of loneliness among visually impaired elderly persons?
4. What is the effect of a multidisciplinary group rehabilitation program on participation (i.e., the primary outcome) and on physical and psychosocial functioning (i.e., the secondary outcomes)?

In order to answer the research question, two studies were performed: a cross-sectional study and a pilot intervention study. In chapter 2, the methodologies of both studies are described. The cross-sectional study included 173 visually impaired elderly persons aged 55 years and over, who were referred to Royal Dutch Visio, region North Netherlands, in the year preceding the data collection. Data for this cross-sectional study were collected by means of telephone interviews. In addition to self-reported performance of participation, participation restrictions and loneliness were assessed as well as the determinants of participation and loneliness. To compare the degree of participation and loneliness of the visually impaired elderly with that of normally sighted peers, three reference data sources were used: (1) National Survey on Living Conditions (POLS) of Statistics Netherlands (CBS); (2) the Amenities and Services Utilization Survey (AVO) of the Social and Cultural Planning Office (SCP); and (3) the Longitudinal Aging Study Amsterdam (LASA).

Based on the results of the cross-sectional study, as well as three focus group interviews and an expert meeting, we developed the multidisciplinary group rehabilitation program *Visually Impaired elderly Persons Participating (VIPP)*. This program aimed to enhance participation in society of the visually impaired elderly. The 20-week program consisted of four components: (1) training of practical skills; (2) education, social interaction, and counseling and training of problem-solving skills; (3) individual and group-goal setting; and (4) a home-based physical exercise program. The effect of the *VIPP*-program was tested in a pilot study with a single group pre-test post-test design. This intervention study included 29 visually impaired elderly persons who formerly participated in the cross-sectional study. Data with respect to the primary outcome of the study (i.e., participation) and the secondary outcome (i.e., psychosocial functioning) were collected by face-to-face interviews. Field-based assessments of physical fitness were used to assess the secondary outcome of physical functioning. Data were collected at baseline (pre-test), half-way through the intervention, immediately after the intervention (post-test) and six months later (long-term follow-up).

Chapter 3 addresses the first research questions with respect to participation in society of the visually impaired elderly. In this thesis, we designated four chapters of the ICF-component 'Activities and Participation', that represent participation: (1) domestic life, (2) interpersonal interactions and relationships, (3) major life areas, and (4) community, social and civic life. The results showed that the majority of the visually impaired elderly was engaged in household activities, in shopping, in socializing with family, friend and neighbors, in hobby activities, and in activities of clubs or associations. Only a minority was engaged in going out to recreational, cultural and public places. Comparison with population-based reference data showed that the visually impaired elderly participated less in household activities and went less often to recreational places. No differences were found for the 'interpersonal interactions and relationships' domain of participation. With respect to participation restrictions, we found that 94% of the visually impaired elderly experienced restrictions in one or more domains of participation. The results of the cross-sectional study indicate that the visually impaired elderly do participate in society, but that in some specific domains they participate less than their peers and that participation restrictions are prevalent. These restrictions may affect the visually impaired elderly, since participation has a positive influence on physical and mental health, and on quality of life.

The study described in Chapter 4 aimed to identify factors that influence the level of participation of the visually impaired elderly. Insight in these factors is necessary for the development of the multidisciplinary group rehabilitation program for the pilot intervention study. The impact of the various factors was investigated according to the biopsychosocial model. To examine the associations of the three components of this model with participation, a hierarchical model approach was applied. Of the biological factors,

vision-related variables (i.e., severity, duration and primary cause of the visual impairment) had no effect on participation. In contrast, perceived physical fitness was associated with participation in domestic life. With respect to the social status variables (i.e., partner status, social network size and social support), social network size was associated with participation in major life areas (i.e., voluntary work). The multivariate hierarchical regression analyses showed that the psychological component (i.e., mental health, helplessness, and the self-management abilities self-efficacy and taking initiatives) contributed to the explained variance of participation across the domains. A significant association was only found for helplessness and participation in domestic life. Perceived importance of participation appeared to be a major determinant of participation. Importance refers to the value that an individual attaches to a specific domain of participation. The results of the study presented in this chapter indicate that the rehabilitation program that will be developed and aims to enhance the level of participation should have a multidisciplinary approach, including physical, psychological and social work intervention techniques.

Chapter 5 focuses on loneliness among the visually impaired elderly. Loneliness is an unpleasant experience, encompassing a lack of (quality of) certain relationships. The purpose of the study described in this chapter was twofold: (1) to identify the degree to which visually impaired elderly experience feelings of loneliness as compared to their normally sighted peers; and (2) to examine the self-management abilities self-efficacy and taking initiatives as determinants of loneliness. Self-management abilities are internal resources which refer to behavioral and cognitive abilities that people use to manage their external resources such as friends and social support. The results of the cross-sectional study showed that loneliness was present in 50% of the visually impaired study population. In comparison, 29% of the normally sighted reference population experienced loneliness, which is a significant lower percentage. In addition, the average loneliness score in the study group was higher than in the reference population indicating that the visually impaired elderly perceive more loneliness. A multivariate hierarchical regression analysis showed that the self-management ability self-efficacy was the strongest determinant of loneliness. In addition, partner status and self-esteem were associated with loneliness. Vision-related variables (i.e., severity and duration of the visual impairment) were not associated with loneliness. In conclusion, this study indicate that the visually impaired elderly are a high-risk group for loneliness. Furthermore, our results suggest that self-management training provides the visually impaired elderly with skills and resources to manage the practical, social and emotional consequences of vision loss and may therefore be effective in reducing feelings of loneliness among the visually impaired elderly.

Chapter 6, 7 and 8 present the results of the pilot intervention study on the effectiveness of the multidisciplinary group rehabilitation program *VIPP*. Chapter 6 focuses on the effectiveness of *VIPP* on four aspects of participation: (1) frequency; (2) restrictions; (3) satisfaction; and (4) autonomy. In this study, the Utrecht Scale for Evaluation of Rehabilitation - Participation (USER-P-version 8) and the Impact on Participation and Autonomy questionnaire (IPA) were used to assess these four aspects of participation. Although at scale level there were no statistically significant changes, the effect sizes indicated a small decrease in restrictions in participation and a small increase in satisfaction with participation, as well as a medium improvement for autonomy outdoors. At item level, improvements tended to occur in frequency of housekeeping, in restrictions in housekeeping and outdoor activities, and in satisfaction with the partner relationship. In addition, satisfaction with leisure indoors and autonomy regarding using leisure time tended to increase. The tentative conclusion of the pilot study is that the *VIPP*-program modestly benefits perceived restrictions in participation, satisfaction with participation and autonomy outdoors of the visually impaired elderly.

The study presented in Chapter 7 aimed to examine the effects of the *VIPP*-program on two indicators of physical functioning, namely aerobic endurance and functional mobility. The 2-minute step test and the Timed Up and Go test (TUG) were used as performance-based measures of aerobic endurance and functional mobility, respectively. The results showed that both aerobic endurance and functional mobility improved not only immediately after the intervention but at long-term follow-up as well. The effect sizes were moderate to large.

In Chapter 8, the effectiveness of the pilot study on five indicators of psychosocial functioning (i.e., adaptation to vision loss, helplessness, self-efficacy, mental health and fear of falling) is described. We found statistically significant changes for three out of the five psychosocial outcome measures. There was an improvement in adaptation to vision loss and self-efficacy, and the feelings of helplessness decreased (medium to large effect sizes). The results suggested that the *VIPP*-program has both short- and long-term benefits. Immediately after completion of the intervention, we found an increase in adaptation to vision loss and self-efficacy as well as a better mental health. In addition, helplessness and generic and vision-specific fear of falling decreased. The 6-months follow-up measure indicated an increase in adaptation to vision loss, less feelings of helplessness, a better mental health and less vision-specific fear of falling. In contrast, we found a decrease in self-efficacy and an increase in generic fear of falling.

The pilot intervention study is a first step toward documenting the effectiveness of the newly developed multidisciplinary group rehabilitation program *VIPP*. Although the findings are based on a small-scale study, the results justify the conclusion that the program has the potential to improve the various factors of participation not only directly, but also indirectly by changing the influencing factors of participation (i.e., physical and psychosocial functioning).

In the final chapter, the results of this thesis are summarized and discussed, and implications for practice and research are addressed. The results of the cross-sectional study underscore the prevalence of restrictions in participation among the visually impaired elderly. Despite these restrictions, the visually impaired elderly do participate in society. However, they participate less in society compared to peers. Perceived importance appears to be a major determinant of participation. Physical health, along with social and psychological status, also affect participation. The results showed, in addition, that the visually impaired elderly are at risk for loneliness. The self-management ability self-efficacy is the strongest determinant of loneliness. Future studies have to show if factors that were not assessed in this thesis, such as environmental factors, contribute to the explained variance of participation and loneliness.

The pilot intervention study on the effectiveness of the *VIPP*-program showed that the program modestly benefits the subjective aspects of participation (i.e., restrictions, satisfaction, and autonomy). With respect to the secondary outcome measures, this thesis showed that participation in the *VIPP*-program improves physical and psychosocial functioning. These results are a good basis for the further development and implementation of the *VIPP*-program. Based on the information that was collected during the evaluation sessions with the participants and with the supervisors, recommendations are made regarding the target population, the group composition, the content, duration and frequency of the *VIPP*-program, as well as regarding the individual goals, and the feasibility of the home-based exercise component of the program. The effectiveness of the *VIPP*-program needs to be endorsed in future further studies, preferably in a randomized controlled design. Moreover future research may provide insight in what makes the *VIPP*-program work.

Samenvatting

Van de visueel beperkten in Nederland is 79% 65 jaar of ouder. Door de vergrijzing neemt het aantal personen met een visuele beperking toe. Visusverlies heeft een grote impact op het dagelijks functioneren en vormt een bedreiging voor de onafhankelijkheid van visueel beperkten. Eerder onderzoek onder visueel beperkte ouderen heeft zich vooral gericht op klinische en functionele uitkomstmaten. Weinig kennis is er over sociale uitkomstmaten zoals participatie in het maatschappelijke leven. Het concept "participatie" is door de Wereldgezondheidsorganisatie (WHO) geïntroduceerd in de Internationale Classificatie van het menselijke Functioneren (ICF; WHO, 2001) en wordt gedefinieerd als "deelname aan het maatschappelijk leven". Kennis over participatie is belangrijk, niet alleen vanuit het perspectief van het individu, maar ook vanuit het perspectief van de maatschappij: het geeft een indruk van de mate waarin mensen 'meedoen'. Het doel van dit proefschrift is: (1) inzicht krijgen in de mate van participatie van visueel beperkte ouderen en de beïnvloedende factoren van participatie; en (2) het ontwikkelen en testen van een multidisciplinair groepsrevalidatieprogramma ter bevordering van de participatie van visueel beperkte ouderen. Deze doelen hebben tot vier onderzoeksvragen geleid die in dit proefschrift beantwoord zullen worden:

1. In welke mate participeren visueel beperkte ouderen in de maatschappij?
2. Welke biologische, sociale en psychologische factoren beïnvloeden de participatie van visueel beperkte ouderen?
3. Wat is de prevalentie van eenzaamheid onder visueel beperkte ouderen en wat zijn determinanten van eenzaamheid onder deze groep?
4. Wat is het effect van een multidisciplinair groepsrevalidatieprogramma op participatie (primaire uitkomstmaat) en op fysiek en psychosociaal functioneren (secundaire uitkomstmaten)?

Om deze onderzoeksvragen te kunnen beantwoorden zijn twee deelonderzoeken uitgevoerd: een cross-sectionele studie en een pilot interventie studie. In hoofdstuk 2 wordt de methodologie van beide onderzoeken beschreven. Voor de cross-sectionele studie zijn 173 visueel beperkte ouderen geïncludeerd die 55 jaar of ouder zijn en die in het jaar voorafgaand aan de dataverzameling doorverwezen zijn naar een expertisecentrum voor visueel beperkten (Koninklijke Visio, regio Noord-Nederland). De data voor de cross-sectionele studie zijn verzameld door middel van telefonische interviews. Behalve de mate van participatie zijn ervaren beperkingen in participatie en eenzaamheid gemeten, evenals de determinanten van participatie en eenzaamheid. Om de mate van participatie en eenzaamheid van visueel beperkte ouderen te kunnen vergelijken met die van goedziende ouderen is gebruik gemaakt van drie referentie datasets: (1) Permanent Onderzoek LeefSituatie (POLS) van het Centraal Bureau voor de Statistiek (CBS); (2) Aanvullend Voorzieningengebruik Onderzoek (AVO) van het Sociaal en Cultureel Planbureau (SCP); en (3) Longitudinal Aging Study Amsterdam (LASA).

Op basis van de resultaten van de cross-sectionele studie, een drietal focusgroep interviews en een expertmeeting is het multidisciplinaire groepsrevalidatieprogramma *Actief Meedoen (Visually Impaired elderly Persons Participating – VIPP)* ontwikkeld met als doel de participatie van visueel beperkte ouderen te bevorderen. Dit 20-weken durende programma bestaat uit vier componenten: (1) training van praktische vaardigheden; (2) educatie, uitwisseling en counseling van probleemoplossende vaardigheden; (3) werken aan individuele en groepsdoelen; en (4) een thuisbeweegprogramma met telefonische coaching. De effectiviteit van *Actief Meedoen* is in een pilotstudie met een single group pre-test post-test design onderzocht. Voor de interventiestudie zijn 29 visueel beperkte ouderen geïncludeerd die eerder deelgenomen hebben aan de cross-sectionele studie. Data met betrekking tot de primaire uitkomstmaat (participatie) en de secundaire uitkomstmaat (psychosociaal functioneren) zijn verzameld door middel van face-to-face interviews. Daarnaast zijn fitheidstesten afgenomen om het fysiek functioneren als secundaire uitkomstmaat te bepalen. Het effect van het programma is op vier momenten gemeten: voor aanvang (pre-test), na 12 weken, direct na afloop (post-test) en zes maanden na afloop van het programma (follow-up).

Hoofdstuk 3 richt zich op de eerste onderzoeksvraag met betrekking tot de mate van participatie van visueel beperkte ouderen. In dit proefschrift zijn vier domeinen van de ICF-component 'Activiteiten en Participatie' gebruikt om participatie te operationaliseren: (1) huishouden; (2) tussenmenselijke interacties en relaties; (3) belangrijke levensgebieden; en (4) maatschappelijk, sociaal en burgerlijk leven. De resultaten laten zien dat de meerderheid van de visueel beperkte ouderen huishoudelijke activiteiten uitvoert, boodschappen doet, contacten heeft met familie, vrienden en buren, regelmatig een hobby beoefent, en actief lid is van een vereniging. Een klein deel van de onderzoeksgroep bezoekt een recreatiegebied, maakt een cultureel uitstapje of gaat naar een restaurant of café. In vergelijking met de referentiedata van goedziende ouderen, voeren visueel beperkte ouderen minder vaak huishoudelijke activiteiten uit en bezoeken zij minder vaak een recreatiegebied. Er zijn geen verschillen gevonden met betrekking tot het domein 'tussenmenselijke interacties en relaties'. Hoewel visueel beperkte ouderen participeren, ervaart 94% van hen beperkingen in één of meer participatiedomeinen. Uit de cross-sectionele studie kan geconcludeerd worden dat visueel beperkte ouderen participeren in de maatschappij, maar dat zij in bepaalde domeinen minder participeren dan hun leeftijdsgenoten en dat de prevalentie van ervaren beperkingen in participatie hoog is. Deze achterstand en beperkingen in participatie kunnen nadelige gevolgen hebben voor de visueel beperkte ouderen, omdat participatie een positieve invloed heeft op de fysieke en mentale gezondheid en, meer algemeen, op de kwaliteit van leven.

De studie die in hoofdstuk 4 wordt beschreven heeft tot doel beïnvloedende factoren van participatie van visueel beperkte ouderen te identificeren. Inzicht in deze factoren is noodzakelijk voor de ontwikkeling van het revalidatieprogramma voor de interventiestudie. De impact van de verschillende factoren is volgens het biopsychosociale model onderzocht, waarbij een hiërarchisch onderzoeksmodel is gebruikt om de associaties tussen de drie componenten van het biopsychosociale model en participatie te onderzoeken. Van de biologische factoren blijken de visus-gerelateerde factoren (ernst, duur en primaire oorzaak van de visuele beperking) niet samen te hangen met participatie. Fysieke fitheid daarentegen hangt samen met participatie in het huishoudelijke domein. Met betrekking tot de sociale factoren (partner status, omvang sociaal netwerk en sociale steun) is een samenhang gevonden tussen de omvang van het sociale netwerk en participatie in belangrijke levensgebieden (vrijwilligerswerk). De multivariate hiërarchische regressie analyses tonen aan dat de psychologische factoren (mentale gezondheid, hulpeloosheid en de zelfmanagement vaardigheden self-efficacy en initiatief nemen) bijdragen aan de verklaarde variantie van participatie binnen de verschillende domeinen. Een significante samenhang is alleen gevonden tussen hulpeloosheid en participatie in het huishoudelijke domein. Het belang dat visueel beperkte ouderen hechten aan participatie in een bepaald domein is echter de belangrijkste determinant van participatie. De bovenstaande resultaten impliceren dat het te ontwikkelen revalidatieprogramma ter bevordering van de participatie van visueel beperkte ouderen een multidisciplinair karakter dient te hebben en dat het zowel fysieke en psychologische, als sociale componenten dient te bevatten.

Hoofdstuk 5 heeft als onderwerp de eenzaamheid onder de visueel beperkte ouderen. Eenzaamheid is een negatieve situatie, gekenmerkt door een gemis aan (kwaliteit van) bepaalde relaties. Het doel van de studie die in dit hoofdstuk wordt beschreven is tweevoudig: (1) het bepalen in welke mate visueel beperkte ouderen gevoelens van eenzaamheid ervaren in vergelijking met goedziende leeftijdsgenoten; en (2) het bepalen van determinanten van eenzaamheid met een focus op de zelfmanagementvaardigheden self-efficacy en initiatief nemen. Zelfmanagementvaardigheden zijn interne hulpbronnen, zoals cognitieve vaardigheden, die nodig zijn om externe hulpbronnen, bijvoorbeeld vrienden en sociale steun, te managen. Resultaten van de cross-sectionele studie tonen aan dat 50% van de visueel beperkte ouderen eenzaam is en dat is aanzienlijk meer dan in de goedziende referentiegroep waar 29% gevoelens van eenzaamheid ervaart. Tevens is de gemiddelde eenzaamheidscore van de onderzoeksgroep hoger dan die van de referentiegroep. Een multivariate hiërarchische regressie analyse laat zien dat de zelfmanagementvaardigheid self-efficacy de belangrijkste determinant is van eenzaamheid. Daarnaast hangen partner status en zelfwaardering samen met gevoelens van eenzaamheid. Visus-gerelateerde variabelen, zoals ernst en duur van de visuele beperking, hangen niet samen met

eenzaamheid. Geconcludeerd kan worden dat visueel beperkte ouderen gevoelens van eenzaamheid ervaren en dat ze een risicogroep zijn als het gaat om eenzaamheid. De beïnvloedende factoren wijzen uit dat training van zelfmanagementvaardigheden, waarbij visueel beperkte ouderen vaardigheden aanleren die hen helpen om te gaan met de fysieke, sociale en emotionele gevolgen van het visusverlies, mogelijk effectief is op het verminderen van eenzaamheidsgevoelens.

In hoofdstuk 6, 7 en 8 worden de resultaten gepresenteerd van de pilot interventiestudie naar de effectiviteit van het multidisciplinaire groepsrevalidatieprogramma *Actief Meedoen*. Hoofdstuk 6 beschrijft de effecten van het programma op vier aspecten van participatie: (1) frequentie; (2) ervaren beperkingen; (3) tevredenheid; en (4) autonomie. De Utrechtse Schaal voor Evaluatie van Revalidatie - Participatie (USER-P-versie 8) en de Impact op Participatie en Autonomie (IPA) zijn in deze studie gebruikt voor het meten van deze vier aspecten van participatie. Hoewel er op schaalniveau (alle activiteiten samengevat) geen statistisch significante veranderingen in participatie zijn, blijkt uit de berekening van de effect sizes dat er een kleine afname is in ervaren beperkingen, een kleine toename in tevredenheid, en tevens een medium toename in autonomie buitenshuis. Op item-niveau blijkt dat deelnemers na de interventie vaker huishoudelijke taken uitvoeren en hier ook minder beperkingen in ervaren, en dat ze minder beperkingen ervaren in activiteiten buitenshuis en meer tevreden zijn met de partnerrelatie. Er lijkt ook een toename in tevredenheid met vrijetijdsbesteding binnenshuis en in autonomie in vrijetijdsbesteding te zijn. De voorlopige conclusie van deze pilot interventiestudie is dat *Actief Meedoen* leidt tot een afname van ervaren beperkingen, en een toename van tevredenheid met participatie en autonomie buitenshuis.

De studie die in hoofdstuk 7 wordt beschreven, heeft tot doel de effecten van *Actief Meedoen* op twee indicatoren van fysiek functioneren te bepalen, namelijk het aerobe uithoudingsvermogen en de functionele mobiliteit. De 2-minuten step test en de Timed Up and Go test (TUG) zijn gebruikt om respectievelijk het aerobe uithoudingsvermogen en de functionele mobiliteit te meten. Uit de resultaten blijkt dat zowel het aerobe uithoudingsvermogen als de functionele mobiliteit tijdens de onderzoeksperiode statisch significant verbeteren, zowel direct na afloop van de interventie als op lange termijn. Het gaat om medium tot grote effect sizes.

In hoofdstuk 8 wordt de effectiviteit van het programma op vijf indicatoren van psychosociaal functioneren onderzocht, namelijk psychosociale aanpassing aan het visusverlies, hulpeloosheid, self-efficacy, mentale gezondheid en valangst. Voor drie van deze vijf psychosociale uitkomstmaten is een significante verandering gevonden. Na de interventie is er een toename in de psychosociale aanpassing en in self-efficacy en is de hulpeloosheid afgenomen. Het gaat om medium tot grote effect sizes. De resultaten laten zien dat *Actief Meedoen* zowel op de korte- als op de lange termijn positieve effecten heeft.

Direct na afloop van de interventie is de psychosociale aanpassing en mentale gezondheid verbeterd, en is er een toename van de self-efficacy. Daarnaast nemen hulpeloosheid en visus-gerelateerde valangst af. Op de lange termijn is er een toename van de psychosociale aanpassing, een afname in gevoelens van hulpeloosheid, een betere mentale gezondheid en minder visus-gerelateerde valangst. Daarentegen, vinden we een afname in self-efficacy en een toename van generieke valangst.

De pilot interventiestudie is een eerste stap in het beschrijven van de effectiviteit van het nieuw ontwikkelde multidisciplinaire groepsrevalidatieprogramma *Actief Meedoen*. Hoewel de resultaten gebaseerd zijn op een kleinschalige studie is de conclusie gerechtvaardigd dat het programma enerzijds de potentie heeft direct de verschillende aspecten van participatie te bevorderen en anderzijds op indirecte wijze participatie te bevorderen door verandering van de beïnvloedende factoren (fysiek en psychosociaal functioneren).

In het laatste hoofdstuk worden de resultaten van het proefschrift samengevat, bediscussieerd en tevens worden de implicaties voor de praktijk en het onderzoek beschreven. De resultaten van de cross-sectionele studie laten zien dat de prevalentie van beperkingen in participatie hoog is onder visueel beperkte ouderen. Ondanks deze beperkingen participeren visueel beperkte ouderen in de maatschappij, maar wel minder in vergelijking met leeftijdsgenoten. Het belang dat de ouderen hechten aan participatie is een belangrijke determinant van participatie. Daarnaast is het fysiek, sociaal en psychologisch functioneren van invloed op participatie. De resultaten tonen tevens aan dat visueel beperkte ouderen een risicogroep vormen met betrekking tot het hebben van gevoelens van eenzaamheid, en dat self-efficacy als zelfmanagementvaardigheid een belangrijke determinant is van eenzaamheid. Vervolgonderzoek moet uitwijzen of andere factoren die niet gemeten zijn in dit proefschrift, zoals omgevingsfactoren, van invloed zijn op de participatie en eenzaamheid.

Uit de pilotstudie naar de effectiviteit van *Actief Meedoen* blijkt dat het programma voornamelijk een positieve invloed heeft op de subjectieve aspecten van participatie, zoals ervaren beperkingen, tevredenheid en autonomie. Met betrekking tot de secundaire uitkomstmaten laat dit proefschrift zien dat door deelname aan *Actief Meedoen* zowel het fysiek als het psychosociaal functioneren toeneemt. De resultaten van de pilotstudie vormen een goed uitgangspunt voor de verdere ontwikkeling en implementatie van *Actief Meedoen.* Op basis van de informatie die verzameld is tijdens evaluatiebijeenkomsten met zowel de deelnemers als de begeleiders, wordt in dit hoofdstuk een aantal aanbevelingen gedaan met betrekking tot de doelgroep, de samenstelling van de groepen, de inhoud, duur en frequentie van *Actief Meedoen*, de individuele doelen en de haalbaarheid van het thuisbeweegprogramma. Het effect van *Actief Meedoen* dient in vervolgonderzoek bevestigd te worden, bij voorkeur uitgevoerd in een gerandomiseerde en gecontroleerde studie. Tevens dient vervolgonderzoek inzicht te geven in welke componenten van het programma bijdragen aan de gevonden positieve effecten.

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Manna Alma
Groningen, maart 2012

Curriculum Vitae

Manna Alma werd geboren op 8 september 1982 te Coevorden. In 2000 behaalde zij haar Gymnasium diploma aan het Christelijk Lyceum Veenendaal. Vervolgens ging zij Bewegingswetenschappen studeren aan de Rijksuniversiteit Groningen. In 2005 studeerde zij af op “Loneliness in older adults in a nursing home: the effect of a combined group exercise and social skills training”. Na haar afstuderen heeft zij het schakelprogramma Gezondheidswetenschappen, Beleid en Management van de Gezondheidszorg gevolgd aan de Erasmus Universiteit Rotterdam. Gelijktijdig werkte zij als projectmedewerker “Patiëntenstromen op de afdeling plastische chirurgie” bij het Erasmus Medisch Centrum.

In januari 2007 startte zij met haar promotieonderzoek naar de maatschappelijke participatie van visueel beperkte ouderen bij de afdeling Gezondheidswetenschappen, sectie Sociale Geneeskunde van het Universitair Medisch Centrum Groningen. Tijdens haar promotietraject heeft zij verschillende cursussen gevolgd, waaronder statistische methoden, project management en gezondheidsgerontologie. In oktober 2010 won zij tijdens het Nationaal Gerontologiecongres de Janneke Witsenburg Posterprijs voor haar poster “Eenzaamheid en zelfmanagement-vaardigheden bij visueel beperkte ouderen”.

Sinds februari 2011 is Manna werkzaam als onderzoeker op de afdeling Gezondheidswetenschappen, sectie Sociale Geneeskunde van het UMCG. Zij is betrokken bij het project “Help, dement! Patiënt en mantelzorger aan het woord”. Door middel van kwalitatief onderzoek wordt belevingsgerichte gezondheids(zorg)informatie verzameld en op internet beschikbaar gemaakt (www.praten-over-gezondheid.nl) in twee aparte modules over dementie, voor patiënt en mantelzorger.

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